HANDICAPPED INDEPENDENCE ASSISTANCE ACT OF 1983

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON WAYS AND MEANS
HOUSE OF REPRESENTATIVES

NINETY-EIGHTH CONGRESS

SECOND SESSION

ON

H.R. 4437

TO AMEND TITLES XVIII AND XIX OF THE SOCIAL SECURITY ACT TO TREAT CERTAIN SENSORY AND COMMUNICATION AIDS AS MEDICAL AND OTHER HEALTH SERVICES, AND FOR OTHER PURPOSES

FEBRUARY 27, 1984

Serial 98-63

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CONTENTS

	Page
Press release of Friday, February 17, 1984, announcing the hearing	1
H.R. 4437, text	3

WITNESSES

American Association for the Deaf-Blind, Roderick J. McDonald	78
American Council of the Blind, Oral O. Miller	10
American Speech-Language-Hearing Association, Morgan Downey	60
Blasch, Bernard, Sensory Aids Corp	59
Bliss, James C., Telesensory Systems, Inc	16
Brown, Hon. George E., a Representative in Congress from the State of California	7
Cerebral Palsy Center, Syracuse, N.Y., Carol Cohen	75
Cohen, Carol, Cerebral Palsy Center, Syracuse, N.Y	75
Cowley, Tom J., Phonic Ear, Inc	21
Crowley, David, Kurzweil Computer Products	57
Downey, Morgan, American Speech-Language-Hearing Association	60
DuBrucq, Denyse C., Ear Three Systems	81
Ear Three Systems, Denyse C. DuBrucq	81
Elliott, John Doyle, Townsend Plan National Lobby	93
Follette, Delores, Carmichael, Calif	79
Kurzweil Computer Products, David Crowley	57
McDonald, Roderick J., American Association for the Deaf-Blind	78
Miller, Oral O., American Council of the Blind	10
Phonic Ear, Inc., Tom J. Cowley	21
Prentke Romich Co., Barry Romich	56
Romich, Barry, Prentke Romich Co	56
Sensory Aids Corp., Bernard Blasch	59
Stepplins, Kurt, Triformation Systems, Inc	58
Telesensory Systems, Inc., James C. Bliss	16
Townsend Plan National Lobby, John Doyle Elliott	93
Triformation Systems, Inc., Kurt Stepplins	58

SUBMISSIONS FOR THE RECORD

American Foundation for the Blind, Inc., Glenn M. Plunkett, statement	95
Blinded Veterans Association, Thomas H. Miller, statement	97
Center for the Partially Sighted, Samuel Genensky, letter and attachments	98
Dayton Public Schools, Patricia F. Skinner, letter	101
Fitzwater, Beverly Jean, Kansas City, Mo., letter	101
Gorman School, Dayton, Ohio, Carol Suddath, letter	102
Hayward High School, Hayward, Calif., Joan T. Harris, letter	103
Hearing Society for the Bay Area, Inc., John L. Darby, letter	103
Kinnaird, John O., Nottingham, Pa., letter	103
Matsui, Hon. Robert T., a Representative in Congress from the State of California, statement	9
Mazuzan, Marsinah, Bethesda, Md., letter	104
Neurological Rehabilitation Associates, Joan A. Rawlings, letter	104
North Carolina Memorial Hospital, Stanley J. Martinkosky, letter	105
Self Help for Hard of Hearing People, Inc., Howard E. Stone, Sr., statement	105
Sonies, Barbara C., Potomac, Md., letter	106
Stone, Maureen, University Park, Md., letter	107
Subrahmanyam, Carol, Kansas City, Mo., letter	102
Susnik, Jackie L., Huber Heights, Ohio, letter	107

THE HANDICAPPED INDEPENDENCE ASSISTANCE ACT OF 1983

MONDAY, FEBRUARY 27, 1984

HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON HEALTH,
Washington, D.C.

The subcommittee met at 2 p.m., pursuant to notice, in room 1100, Longworth House Office Building, Hon. Robert T. Matsui presiding.

[The press release announcing the hearing and a copy of the bill, H.R. 4437, follow:]

[Press release of Friday, Feb. 17, 1984]

HON. ANDY JACOBS, JR. (D., IND.), CHAIRMAN, SUBCOMMITTEE ON HEALTH, COMMITTEE ON WAYS AND MEANS, TODAY ANNOUNCED A HEARING ON H.R. 4437, THE HANDICAPPED INDEPENDENCE ASSISTANCE ACT OF 1983, TO BE HELD ON FEBRUARY 27, 1984

The Honorable Andy Jacobs, Jr. (D., Ind.), Chairman of the Subcommittee on Health of the Committee on Ways and Means, U.S. House of Representatives, announced today that the Subcommittee will hold a hearing on H.R. 4437 (Messrs. Brown of Calif., Heftel, Matsui, Miller of Calif., and Zschau), the "Handicapped Independence Assistance Act of 1983." The hearing will be held on Monday, February 27, 1984, in Room 1100, Longworth House Office Building, beginning at 2:00 p.m. Immediately preceding the hearing, there will be a display in the hearing room of sensory and communication aids, equipment and devices used by individuals who are blind, severely visually impaired, deaf, severely hearing impaired or vocally impaired.

BACKGROUND

H.R. 4437 would provide for medicare and medicaid coverage of sensory and communication aids which are designed to substantially reduce or eliminate handicaps caused by blindness, deafness, a severe hearing or visual impairment, or the inability to communicate vocally.

The bill would limit the amount of incurred expenses for which medicare reimbursement would be made for such items and related services to $5,000 in any calendar year, and no more than $15,000 in any five consecutive years.

DETAILS FOR SUBMISSION OF REQUESTS TO BE HEARD

Individuals and organizations interested in presenting oral testimony before the Subcommittee must submit their requests to be heard by telephone to Harriett Lawler ((202) 225-3627) no later than noon, Thursday, February 23, 1984, to be followed by a formal written request to John J. Salmon, Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. Notification to those scheduled to appear will be made by telephone as soon as possible after the filing deadline.

In order to assure the most productive use of the limited amount of time available to question witnesses, witnesses scheduled to appear before the Subcommittee are required to submit 100 copies of their prepared statements to the main Committee

office, Room 1102 Longworth House Office Building, at least 24 hours in advance of their scheduled appearance.

Each statement to be presented to the Subcommittee or any written statement submitted for the record must contain the following information:

(1) The name, full address, and capacity in which the witness will appear (as well as a telephone number where he or his designated representative may be reached); (2) A list of any clients or persons, or any organization for whom the witness appears; and (3) A topical outline or summary of comments and recommendations.

WRITTEN STATEMENTS IN LIEU OF PERSONAL APPEARANCE

For those who wish to file a written statement for the printed record of the hearing, six copies are required and may be submitted by the close of business Monday, March 12, 1984, to John J. Salmon, Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, Room 1102 Longworth House Office Building, Washington, D.C. 20515. An additional supply of statements for the printed record may be furnished for distribution to the press and public if supplied to the Committee office before the hearing.

I

98TH CONGRESS
1ST SESSION

H. R. 4437

To amend title VIII and XIX of the Social Security Act to treat certain sensory and communication aids as medical and other health services, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 17, 1983

Mr. BROWN of California (for himself, Mr. HEFTEL of Hawaii, Mr. MATSUI, Mr. MILLER of California, and Mr. ZSCHAU) introduced the following bill; which was referred jointly to the Committees on Ways and Means and Energy and Commerce

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A BILL

To amend title VIII and XIX of the Social Security Act to treat certain sensory and communication aids as medical and other health services, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE

SECTION 1. This Act may be cited as the "Handicapped Independence Assistance Act of 1983".

FINDINGS

SEC. 2. The Congress finds that—

(1) the increased availability and use of technologically advanced sensory and communication aids, equipment, and devices by individuals who are blind, severely visually impaired, deaf, severely hearing impaired, or vocally impaired would reduce the handicaps of such individuals with respect to employment, education, and self-care;

(2) such sensory and communication aids, equipment, and devices would open many new job opportunities for their users, but are beyond the financial means of many such individuals;

(3) although payment for such aids, equipment, and devices is not expressly prohibited by statutes authorizing Federal health insurance programs, regulations of both Federal and State agencies result in widespread denials of such payments; and

(4) wider acquisition of such aids, equipment, and devices by persons with disabilities would benefit the national economy, disabled persons, and their families through increased employment, independence, and improved education for such persons, and is therefore in the national interest.

AMENDMENTS TO SOCIAL SECURITY ACT

SEC. 3. (a)(1) Section 1861(s) of the Social Security Act is amended—

(A) by redesignating paragraphs (11) through (14) as paragraphs (12) through (15) respectively;

(B) by striking out "and" at the end of paragraph (9);

(C) by striking out the period at the end of paragraph (10) and inserting in lieu thereof "; and"; and

(D) by inserting after paragraph (10) the following new paragraph:

"(11) sensory and communication aids designed to substantially reduce or eliminate handicaps to employment and education caused by blindness, deafness, a severe hearing or visual impairment, or the inability to communicate vocally, including training in the use of such aids.".

(2) Section 1864(a) of such Act is amended by striking out "paragraphs (11) and (12)" and inserting in lieu thereof "paragraphs (12) and (13)".

(b) Section 1862(a)(1) of such Act is amended—

(1) by striking out "and" at the end of subparagraph (B);

(2) by striking out the semicolon at the end of subparagraph (C) and inserting in lieu thereof ", and"; and

(3) by adding at the end thereof the following new subparagraph:

"(D) in the case of items and services described in section 1861(s)(11), which are not reasonable and necessary for reducing or eliminating handicaps caused by blindness, deafness, a severe hearing or visual impairment, or the inability to communicate vocally;".

(c) Section 1833 of such Act is amended by adding at the end thereof the following new subsection:

"(k) With respect to expenses incurred for items and services described in section 1861(s)(11), no more than $5,000 in any calendar year, and no more than $15,000 in any five consecutive calendar years, shall be considered as incurred expenses for purposes of subsections (a) and (b).".

(d) Section 1905(a)(12) of such Act is amended by inserting after "devices" the following: ", including sensory and communication aids described in section 1861(s)(11)".

(e) The amendments made by this Act shall be effective with respect to items and services furnished on or after January 1, 1985.

Mr. MATSUI. Today, the Subcommittee on Health will discuss H.R. 4437, sponsored by Congressman George Brown of California. At this time I would like to call the sponsor of the bill, the Honorable George Brown, to testify.

STATEMENT OF HON. GEORGE E. BROWN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. BROWN. Thank you very much, Mr. Chairman, for this opportunity to testify on H.R. 4437, the Handicapped Independence Assistance Act of 1983. I recognize the great demands which exist on this very important Committee on Ways and Means. I think it is very fortunate that we have the opportunity to have this hearing devoted to the problems of the handicapped and what can be done through relatively minor changes in the Social Security Act to facilitate the further integration of the handicapped into the mainstream of our economic society.

I think all the committee knows that this bill is a slightly modified counterpart to a similar bill introduced in the Senate by Senator Matsunaga, who has been concerned about the issues of the handicapped for many years. And I am pleased and delighted to be able to join with you and a number of other Members in the House in sponsoring this legislation which he has introduced.

My own interest in this area began in the early sixties when I served on the Veterans Affairs and the Science Committee, which was then chaired by Olin "Tiger" Teague, who was himself a disabled veteran. We shared a concern for the effective utilization of science and technology to meet the needs of those with disabilities.

We have seen many technological advances since the sixties. In the last decade we have taken technology which has been developed for one arena and successfully transferred its application to areas different from the original intentions. For instance, the technological advances developed originally for NASA have been transferred to rehabilitation engineering. We have only to look at rechargeable pacemakers and increasingly sophisticated prosthetic limbs to see the evidence of this transfer of technological innovations.

Sensory and communication aids for the visually, hearing, and speech disabled have also benefited from technological advances. Sensory and communication aids increase the communication capabilities of those with sensory impairments. For instance, Phonic Ear developed in the last decade an FM radio transmission system for use in educating the hearing impaired, and speech synthesizers are now available for nonoral individuals. I should point out we have examples of many of these in the rear of the hearing room and I have been impressed by the improvements since the last time I have had an opportunity to review the similar aids.

The benefit to this Nation of making these communication aids available to sight, hearing, and speech-impaired individuals, thereby allowing independence and productive employment for those individuals, in place of continued dependence on public support, is encouraging in this time of staggering deficits.

The number of legally blind, profoundly and severely hearing impaired, and severely vocally impaired persons who are enrolled in

medicare and whose family incomes are at or below the poverty level is about 81,300, according to the 1981 "Social Security Bulletin," the "Digest of Data on Persons with Disabilities," and a 1978 "Survey of Disability and Work." About half of these persons would be appropriate candidates for employment. If we assume that only 10 percent of these presently have sensory and communication aids available to them, then we have a target population of nearly 36,000 individuals who have the potential for gainful employment, and who could be assisted to full independence by the technology available today. But the cost of many of these communication devices is often prohibitive; thus, many who could benefit are often denied the use of communication devices because of their finances.

For example, a hand-held voice synthesizer, the HandiVoice, could free many vocally impaired individuals to pursue education and employment. But, at a cost of $2,650.00, many parents of the vocally impaired, and vocally impaired adults, find this device financially out of reach. And yet, if we were to reach our target population of employable, low income disabled persons, savings in reduced welfare payments, social security disability insurance payments, and medicare payments, and increased Federal, State, and local tax revenues could quite possibly reach $15.5 million by the end of the second year of medicare part B coverage of HandiVoice, Phonic Ear, and similar communication devices.

Medicare part B does not specifically exclude coverage of communication devices. It has achieved that effect, however, in most cases, by denying that the communication devices are medical necessities. This is absurd when we realize that the devices in question may provide the patient with his or her only means of communication of even basic needs. It is time that communication aids be recognized for what they are—medically necessary prosthetic devices that are essential in providing handicapped individuals with the opportunity to meet their full potential to communicate, to function, and to be independent.

I am pleased that this subcommittee has been willing to convene this hearing today. I know that the testimony and demonstrations that you will see will prove most informative and persuasive. I urge your favorable action on this most important legislation.

Thank you.

Mr. MATSUI. Thank you very much, Chairman Brown. I appreciate very much the fact that you introduced the legislation and made the request for this hearing.

I would like to inform the ladies and gentlemen of the audience that Congressman Jacobs, the chairman of the Health Subcommittee, wanted to be here this afternoon, but he is in Indiana and got snowed in by the weather. For that reason he is not here this afternoon, but he did want me to express his apologies to all of you who have an interest in this legislation, and the fact that he wanted to be here. The mere fact he called this hearing indicates his interest in this issue.

Of course I would like to introduce the gentleman from Tennessee, Mr. John Duncan, a member of the Ways and Means Health Subcommittee as well.

Do you have any questions, John?

Mr. DUNCAN. I have no questions, Mr. Chairman, thank you. I want to thank our able colleague, Mr. Brown, for his testimony.

Mr. MATSUI. Thank you, George.

Mr. BROWN. Thank you, gentlemen.

Mr. MATSUI. I would like to submit for the record my statement of support for H.R. 4437. Without objection I will submit it at this time. I just might point out without reading the document that we received information from Bob Humphreys, former Commissioner of Rehabilitation Services Administration. He indicates that the costs of H.R. 4437 will be approximately $21.4 million for the first 3 years. After the third year, however, the bill could generate a potential $31 million net gain in the sense that there will be reduced public assistance payments and increased tax revenues. Of course from then on out there should be a revenue positive aspect to this, because there will be more revenues coming into the Treasury than moneys going out. I just want to emphasize that, and would like to submit this document for the record.

[The prepared statement follows:]

STATEMENT OF HON. ROBERT T. MATSUI, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Chariman, thank you for providing me the opportunity to testify before your subcommittee this afternoon and discuss the merits of H.R. 4437, the Handicapped Independence Assistance Act of 1983. I want to express my personal appreciation for your sensitivity toward the needs of America's disabled by agreeing to hold today's hearing.

We are here to review H.R. 4437, which seeks to provide Medicare and Medicaid coverage for sensory and communication aids. These devices enable persons with severe hearing, speech, or visual impairments to strengthen or replace a sense that has been lost or diminished.

Prior to the beginning of this meeting, members of the subcommittee were able to examine in some detail a comprehensive display of these devices. While I still marvel at Annie Sullivan's achievement in breaking through the utter darkness of Helen Keller's world, even a brief examination of these devices demonstrates how they can extend that miracle, by allowing the disabled to harness technological advances and thereby interact more easily with the world. In turn, these instruments will foster even greater independence and self-sufficiency among the sensory impaired.

Given the high cost of this equipment, however, much of the target population cannot afford to purchase it. Their private resources or insurance often are exhasusted on basic medical needs. Third party payers generally do not deem sensory aids as medically necessary and therefore not reimbursable as Durable Medical Equipment.

Our goal is to reverse this practice and secure wider dissemination of sensory and communication aids. H.R. 4437 accomplishes this end by providing assistance through the Medicare and Medicaid programs, primarily to those persons at or below the poverty level and to those who have the potential for employment at or above the Substantial Gainful Activity (SGA) level.

With access to this equipment, the sensory disabled can increase their communications capacity and take advantage of broader educational and employment opportunities. These opportunities can heighten their independence and potential for employment, while lessening their dependence on public assistance services. This change would result in fewer welfare and disability payments, reduce the number of hours for attendant care, and increase federal, state, and local tax revenues.

At this time, I would like to discuss with the subcommittee the specific reasons for my belief that H.R. 4437 will provide benefits that far outweigh its costs.

According to preliminary cost estimates prepared by Bob Humphreys, former Commissioner of the Rehabilitation Services Adminsitration, the likely population eligible for help in purchasing the devices approaches 35,600.[1] The analysis shows

[1] The figures are drawn from the Congressional Research Service's Digest of Data on Persons with Disabilities, the Social Security Administration's 1978 Survey of Disability and Work, and the Social Security Bulletin, Annual Statistical Supplement, 1981.

that over half the potential population, approximately 81,000 persons, has been screened out because of age, severity of disability, or lack of personal motivation.

In each of the first three years in the program proposed by H.R. 4437, it is estimated that thirty percent of the 36,600 individuals eligible will receive the aids. This time lag is due, principally, to supply limitations and Medicare's ability to process potential applicants. Medicare's cost in the first year would total $21.4 million, as eighty percent of the average allowable cost of the devices is approximately $2,000.00 (the average total cost per device is $2,500).

In the out-years, the analysis anticipates significant benefits. By the end of the first three years of Medicare coverage, benefits could reach a potential $31 million in reduced public assistance payments and increased tax revenues.

With Medicare and Medicaid recognizing the need for, and benefits of, sensory aids coverage, we hope that other third-party insurers will begin providing reimbursement as well.

Notwithstanding these important financial benefits, the acquisition of these communication aids will serve an even higher purpose: the lives of the sensory impaired will be enhanced. The wider availability of these aids will benefit individuals such as Delores Follette, one of my constituents from Sacramento, who has come here today to share her experiences and her comments on this legislation.

Unlike Delores Follette, many citizens whose hearing or vision is free from impairment often take for granted these basic human attributes which determine whether one can participate fully in the mainstream of professional, social, and personal activity.

I do not, Mr. Chairman, because I have a hearing impairment. I am fortunate, however, as I have the resources both to seek treatment and to obtain a hearing aid, which permits me to function normally.

Congress created the Medicare and Medicaid programs to assist the elderly and indigent for whom a lack of financial resources made the difference between suffering or coping with health problems. Just as Medicare and Medicaid recognize the need to cover artificial limbs and wheelchairs for those who experience a loss of mobility, who can argue that an inability to "break the sound barrier" deserves less attention?

H.R. 4437 will make that critical difference in the lives of the sensory impaired.

Thank you again, Mr. Chairman, for devoting the time of the subcommittee to this terribly important issue for a segment of the American population whose special needs must not be ignored.

Mr. MATSUI. Of course I would like to mention also, if I may, and give thanks to those individuals who brought the devices today for members of the subcommittee to examine. I was extremely impressed with the state of the art of this technology. I also appreciate the fact that the committee had brought this equipment through our security so we could take a look at it.

At this time I would like to call Mr. Oral O. Miller, the National Representative for the American Council of the Blind.

We will receive your written testimony and, without objection, it will be placed in the record. You are free to read it or summarize it.

STATEMENT OF ORAL O. MILLER, NATIONAL REPRESENTATIVE, AMERICAN COUNCIL OF THE BLIND

Mr. MILLER. Thank you. Thank you, Mr. Chairman. I will summarize the remarks of the written statement.

My name is Oral Miller, and I am the national representative of the American Council of the Blind, which is the largest organization of blind and visually impaired people in the United States. Our members come from all parts of the country and all walks of life, and 16 of our affiliated organizations or chapters are established along special interest, vocational or professional lines such as the National Association of Blind Teachers, Visually Impaired Data Processors—those are computer programers and related posi-

tions—the American Blind Lawyers Association, Visually Impaired Secretarial Transcribers Association—don't worry, I am not going to name all 16 of them. The Randolph-Sheppard Vendors of America and Council of Citizens with Low Vision.

Our other 51 affiliated organizations are established along State and regional lines such as the ACB of California, Tennessee Council of the Blind, ACB of Texas, Oregon Council of the Blind, et cetera. All together we have 67 affiliates reaching from Hawaii on the west to Puerto Rico on the east. We are in very frequent contact with our members by mail and telephone, so we are on a daily basis knowledgeable about their needs and their problems.

We thank you for this opportunity to testify in support of H.R. 4437, the Handicapped Independence Assistance Act of 1983, a very appropriate title I might add, which authorizes medicare/medicaid coverage for sensory and communications aids designed to reduce or eliminate handicaps to education and employment. However, we recommend also that this legislation be amended to include coverage for the cost of maintenance and repair of such sensory and communications aids, since such costs can themselves represent a barrier to the acquisition of these devices. Blind and visually impaired people must often rely on sensory and communication aids to compensate for the lack of sight.

Although I am going to point out right now that aids and appliances cannot take the place of motivation, industry, imagination, ingenuity, flexibility, proper training, but many blind people, especially many newly blinded people, are not employed. Many of them have or are receiving supplemental security income or social security disability insurance and, as a result, they are probably eligible for medicare and medicaid benefits.

Many of them have lost their jobs because of blindness and can't afford the aids and appliances necessary to get them back into the ranks of the employed. Now, what are we talking about when we say sensory and communications aids? They are devices which range from the simple to the complex that help blind people acquire information that is normally acquired by sight.

As an example, 20 years ago the cassette tape recorder was introduced to the American consumer market. The earliest cassette tape recorder cost over $100, was bulky, and lacked good sound quality by today's standards. Yet this new technology was probably the most important advance in communications for blind people since the invention of braille over 150 years earlier. The cassette recorder soon became much more affordable, not because blind people bought the new devices, although many did, but because millions of people around the world saw a use for this new equipment and brought the price down. Today, it is possible to get units for as low as $50.

Another spinoff is the microcassette recorder. That one, very much like the one I have in my hands here, is the size of a package of cigarettes. It is a little recorder which many blind people find is indispensable for note-taking purposes as you probably find the ballpoint pen in your pocket.

Unfortunately, though many other equally useful devices and aids are not mass produced like the recorder, and therefore they are beyond the financial reach of most blind and other disabled

people. An Optacon, for example—that is a brand name—which many of you may have seen demonstrated earlier here today, is an electronic device which converts regular print into a tactical imagine which a blind person can then read. But it costs over $4,000. A VersaBraille, another brand name, which can be used as a braille computer terminal, costs perhaps $6,000. A closed circuit television magnifier which enables people with very limited vision to read greatly magnified print costs over $2,000. These items are costly because development costs are high, and, now, the market is small. This fact, in turn, keeps some of the particularly inventive firms from entering this market, thus further limiting the variety of aids that are available.

How are such aids used nowadays? Well, they are used in many ways, to reduce or eliminate barriers to education and employment. To look at a few examples, a college student can use an inexpensive talking—I'm going to use another brand name—Apple computer, and there are many others, to produce a letter perfect term paper independent of sighted assistance. An editor preparing written copy can do likewise. A tax specialist can use a VersaBraille or MicroBraille hooked to a regular computer printer to prepare tax forms for others. A blind stockbroker can use a talking computer terminal to obtain the latest quotes. And the blind woman in Colorado pioneers new employment opportunities as an airlines reservationist with United Airlines by connecting her braille output terminal to the company's main computer.

All of these people now pay taxes and contribute fully to their communities, no longer needing medicare, medicaid, SSI, or SSDI.

What about the costs? Very important. The U.S. Census Bureau recently reported that the poverty rate is 2½ times greater among disabled working age adults than among their able-bodied counterparts. There are precious few sources of funding for obtaining needed aids. The State rehabilitation agencies, one of the traditional sources, are finding it increasingly more difficult because of greater demands and because of their own shrinking budgets. Some of our own affiliates have tried to help fill this gap by making available low interest loans for this purpose. Also, the Office of Technology Assessment, OTA, found that the assistance generally available for the purchase of such aids is usually limited to the lower cost devices, which although important, this often turns out to be more expensive in the long run, because of income maintenance payments or, in some cases, institutionalization involved in the meantime.

In addition to H.R. 4437 we urge Congress to consider the other financing alternatives suggested in the OTA report. These would include low interest loans, loan guarantees and tax incentives for the purchase of sensory aids and communication aids. As pointed out by Congressman Brown, nothing in present law forbids reimbursement for such aids, but such requests according to OTA are often denied because such technologies just aren't considered medically necessary. Hence, we have the unusual result that a stroke victim who has lost some of his sight may receive physical or speech therapy, but may not get a low vision aid.

Also, the primary focus of the medicare program has been on acute medical problems with little attention given to the ameliora-

tion of chronic disability. In addition to the long-term cost savings suggested by OTA, this legislation would limit coverage to $5,000 in 1 calendar year with a maximum coverage of $15,000 in any 5 consecutive years period, thus making the individual responsible for the excess. Now, this requirement of individual responsibility would guard against the purchase of unnecessary or inappropriate aids.

Finally, since H.R. 4437 already provides for training in the use of such aids, we believe that the coverage for service costs is also a necessary element in the complete package. A complete package of diagnosis, acquisition, training, and service.

In conclusion, we wholeheartedly support H.R. 4437, the cost of which would be minimal as pointed out just a few minutes ago, compared with the amount we spend on income support programs. In 1977 alone, according to one recent estimate, the United States spent over $63 billion on behalf of working aged disabled people. With $47 billion of that for needed welfare and other support programs, $3 billion were earmarked for direct services such as rehabilitation and about $13 billion directed for medical care. This shows clearly that the cost of dependency in this country is too high, especially when sensory and communication aids that are available that, in many cases, would eliminate or reduce the barriers or handicaps to education and employment.

We think the passage of H.R. 4437 is an essential first step toward making that needed technology affordable and accessible to the people who really need it. Again, Mr. Chairman, members of the subcommittee, we want to thank you for giving us this opportunity to share our views with you today.

[The prepared statement follows:]

STATEMENT OF ORAL O. MILLER, NATIONAL REPRESENTATIVE, AMERICAN COUNCIL OF THE BLIND

Mr. Chairman, the American Council of the Blind (ACB) is pleased for this opportunity to testify in support of H.R. 4437: The Handicapped Independence Assistance Act of 1983. This legislation, which authorizes Medicare/Medicaid coverage for sensory and communications aids designed to reduce or eliminate handicaps to education and employment, is an important first step toward making this equipment more widely available to those who need it. We recommend that this legislation should be amended to include coverage for the cost of maintenance and repair of such sensory and communications aids, since such costs can themselves represent a barrier to the acquisition of these devices.

The American Council of the Blind is the largest organization of blind and visually impaired people in the United States. For the past twenty three years we have worked toward improving the lives of this nation's blind and visually impaired citizens through legislation, legal advocacy, and public education. Our members come from all walks of life and reside in all parts of the country. Some Council members own their own businesses or are employed in a variety of occupations including law, teaching, retailing and data processing. These individuals often rely on sensory and communications aids to make their work more productive and competitive with that of sighted co-workers. Many other individuals, particularly newly blinded people, are employed. These individuals often receive supplemental security income or social security disability insurance benefits and may also be eligible for Medicare/Medicaid assistance. These individuals often have lost their jobs as a result of blindness and cannot afford the cost of sensory and communications aids needed to help them regain remunerative employment.

WHAT ARE SENSORY AND COMMUICATIONS AIDS

Generally speaking sensory and communications aids help blind and visually impaired people to acquire information which normally is perceived through the sense

of sight. Sensory and communications aids may be simple inexpensive consumer products or may be costly high technology items which can be afforded only by a small fraction of the total number of potential users.

About twenty years ago, the cassette tape recorder was introduced to the American consumer market. The earliest cassette tape recorder cost over $100, was bulky, and lacked good sound quality by today's standards. Yet this new technology was the most important advance in communications for blind people since the invention of braille over 150 years earlier. The cassette recorder soon became more affordable, not because blind people bought the new devices, although many did, but because millions of sighted people around the world saw a use for this new equipment. As technology advanced, the four track slow speed cassette recorder evolved and today it is used by thousands of blind and physically handicapped people to listen to reading material provided through the Library of Congress. Another example of a useful device which represents a spin-off from the original cassette technology is the microcassette: a cigarette package sized tape recorder which many blind people find as indispensable for note taking as the pen in your pocket.

I mention the cassette recorder as an everyday example of how technology can assist blind and visually impaired persons to maximize their education and their employment potential. The cassette recorder was acquired by many blind people because it was affordable. These machines became affordable because millions of units were manufactured and sold to consumers both blind and sighted alike.

Unfortunately, many other useful devices are not mass produced consumer products which makes their acquisition beyond the financial reach of most blind or other disabled people.

Medicare/Medicaid coverage for sensory and communications aids is necessary because many technologies are not as affordable as the cassette tape recorder. An optacon—a portable electronic reading device which enables blind persons to read independently printed material—costs over $4,000. A VersaBraille, which can be used as a braille output computer terminal, costs over $6,000. A closed-circuit television magnification system which enables a low vision person to read independently can cost over $2,000. The price tags on these devices are high because research and development costs are expensive and because the market for such technologies is small. Accordingly, few units are manufactured thus limiting economies of scale. Because of these and many other factors manufacturers are often unwilling to enter the sensory and communications aids industry which further limits the number and variety of aids available to those who need them.

HOW ARE SENSORY AND COMMUNICATIONS AIDS USED BY BLIND AND VISUALLY IMPAIRED PERSONS TO REDUCE OR TO ELIMINATE HANDICAPS TO EDUCATION OR EMPLOYMENT

Here are just a few examples. A college student uses a talking Apple computer to produce letter perfect term papers and reports without the need for sighted assistance. A tax preparer uses a VersaBraille connected to a printer to aid him in the preparation of income tax forms. A secretary uses the optacon connected to a special typewriter lens to verify the accuracy of her typing. A blind stockbroker uses a talking terminal to obtain the latest stock quotes and therefore is able to compete on a par with his sighted colleagues. A blind woman in the midwest pioneers a new employment opportunity as an airline reservations sales agent by connecting her braille output terminal to the airlines mainframe computer. All of these people are working; they pay taxes and contribute fully to their communities. They no longer need Medicare, Medicaid, Social Security Disability Insurance benefits or any of the other income support offered by our government to blind and other disabled people based upon economic need. And on that note, let me turn now to the question of cost.

ALTERNATIVE FINANCING AND COSTS TO THE HEALTH CARE SYSTEM

As noted earlier, few disabled people can afford to purchase needed technologies. This is because a high percentage of disabled people have low income levels and a disproportionate number have incomes below poverty level. The U.S. Census Bureau recently reported that 26 percent of disabled working age adults have incomes below the poverty line and that this poverty rate is two and one-half times greater than that for nondisabled working age adults.[1] The Office of Technology Assessment

[1] Labor Force Status and Other Characteristics of Persons with Work Disability, Series P-23127, U.S. Census Bureau, 1982; See also "Physical Disability and Public Policy," *Scientific American*, Vol. 248, No. 6, June 1983, p. 42.

(OTA) found in May 1982 that there are "few available methods" for financing needed technologies and that the methods which do exist are available only in selected parts of the country.[2] Our own experience would also support this conclusion. Many of our members have encountered difficulties in obtaining bank loans for the purchase of sensory and communications aids; and rehabilitation agencies, which once were willing to help underwrite the cost of this equipment, find it increasingly difficult to do so as they face higher costs, greater demand for services, and shrinking budgets. Some of our own state affiliated organizations have tried to fill this gap by providing low interest loans for the purchase of sensory and communications aids. Some foundation assistance is available, but unfortunately demand for assistance far outstrips currently available resources.

OTA also found that the financial aid available for the purchase of sensory and communications aids was generally limited to the lower cost devices: "use of such a criterion may fail to identify instances when a greater initial investment might result in a decreased long-term cost and greater functional ability for the individual involved." OTA further observed: "a significant effect of the current system is that in the short-term funds may be saved while in the long-term a greater amount of total funds is expended in, for example, income maintenance payments or institutionalization expenses." [3] It is apparent from the foregoing that many blind and other disabled people cannot afford the cost of sensory and communications aids needed for employment or education; that alternative financing for such equipment is inadequate, and that reimbursement under the Medicare/Medicaid programs is necessary to help blind and other disabled persons to meet the high cost of these aids. In addition to passage of H.R. 4437, we urge Congress to consider the other financing alternatives suggested in the OTA report. These include low interest loans, loan guarantees, and tax incentives for purchase of sensory and communications aids.

We of course are cognizant of the financial state of the Medicare trust fund and accordingly some may oppose, strictly on financial grounds, any new benefit initiatives. Nothing in the present law or regulations prohibits reimbursement for sensory and communications aids. OTA found however that requests for reimbursement for this equipment are often denied because technologies are not considered to be "medically necessary." [4] The primary focus of the Medicare program has been upon acute medical problems and little attention has been given to the amelioration of chronic disability: "a connection needs to be made in these programs between paying for . . . technologies and the potential independence or productivity of disabled people."[5] We also believe that the cost to the Medicare system as a result of H.R. 4437 will be minimal. In addition to the long-term cost savings suggested by OTA, the legislation itself limits coverage to $5,000 in any one calendar year with a maximum coverage of $15,000 in any five consecutive calendar years. Thus, the individual will remain responsible for any costs in excess of the covered amount, and it is quite possible that such excess cost can be substantial given the high initial cost of some sensory and communications aids. Coverage of sensory and communications aids under the Medicare/Medicaid programs cannot be considered a windfall to a recipient since in many cases the individual would continue to bear a significant part of the cost of needed technology. Accordingly, because individuals will be liable for excess costs over the covered amount, H.R. 4437 offers a safeguard against purchase of unnecessary or unsuitable technologies.

Finally, we endorse OTA's recommendation that the cost of repair and maintenance of sensory and communications aids should also be a covered expense. Since H.R. 4437 already provides coverage for training in the use of sensory and communications aids, we believe that coverage for sevice costs is a necessary element in a complete package which includes training, acquisition, and servicing of this equipment.

CONCLUSION

The American Council of the Blind wholeheartedly supports H.R. 4437. The cost of this legislation is de minimis compared to the amount of money which this nation spends on income support programs. In 1977 alone, according to one estimate, this country spent over 63 billion dollars on behalf of working aged disabled people. Of

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[2] "Technology and the Handicapped," a report of the Office of Technology Assessment, May 1982, p. 177.
[3] *Ibid.*, pp. 177-178.
[4] *Ibid.*, p. 177.
[5] *Ibid.*, pp. 177-178.

this total about 47 billion dollars was spent on needed welfare and other support programs. Only about 3 billion dollars was earmarked for direct services such as rehabilitation and about 13 billion dollars was paid for medical care.[6] Thus, the cost of dependency in this nation is too high particularly when sensory and communications aids are available which in many cases can ameliorate handicaps to education and employment.

Last week here in Washington the Institute of Electrical and Electronic Engineers (commonly known as "IEEE") held its centennial convention. With the theme of "Challenge 21" this international organization of 200,000 engineers has committed itself to the development of assistive technologies for disabled persons. We salute IEEE for its commitment in this regard. However, we must continue to devlop new and innovative ways of making technology affordable and accessible to the people who need it. We think the passage of H.R. 4437 is a first step toward achieving this goal.

Mr. MATSUI. Thank you very much, Mr. Miller, for your very important testimony.

We have with us Congressman Moore, a member of the Ways and Means Committee from the State of Louisiana. I would ask Mr. Moore if he has any questions at this time.

Mr. MOORE. No questions, thank you.

Mr. MATSUI. Mr. Duncan.

Mr. DUNCAN. No questions.

Mr. MATSUI. Thank you again, Mr. Miller. We appreciate your very important testimony.

At this time we would like to call the first panel of witnesses. We would like to call James C. Bliss, Tom Cowley, Barry Romich, David Crowley, Guy Carbonneau, and Bernard Blasch.

Will these gentlemen please come up to the podium? As I indicated with Mr. Miller, your written testimony, without objection, will be received for the record. You may, however, read it or summarize it.

At this time I will call first on Mr. Bliss to begin his testimony.

STATEMENT OF JAMES C. BLISS, PH.D., PRESIDENT, TELESENSORY SYSTEMS, INC.

Mr. BLISS. I would like to summarize the written testimony that I presented.

Mr. Chairman and members of the subcommittee, my name is James C. Bliss. I am president and chief executive officer of Telesensory Systems, Inc., a company which manufactures and markets sensory aids for persons who are blind and severely visually impaired. With me are representatives of other companies whose products are displayed at the rear of the hearing room.

First, let me express my personal appreciation for your willingness to hold hearings on H.R. 4437. I am acutely aware of the demands placed on the time of Members of Congress and their staffs, and that it is difficult to make this accommodation. However, I am confident that, after hearing from this panel of witnesses and others who will follow, you will agree that it was time well spent on a vitally important issue, and that enactment of H.R. 4437 is not only desirable, but is in the national interest, and is necessary to the future well-being and independence of thousands of disabled Americans. I particularly appreciate your graciousness in permit-

[6] Monroe Berkowitz, Rutgers University, "Physical Disability and Public Policy", *Scientific American*, Vol. 248, No. 6, June 1983, p. 42.

ting the display of sensory and communication aids in conjunction with this hearing.

The bill that is the subject of this hearing was introduced by Representatives George Brown, Robert Matsui, George Miller, Cecil Heftel, and Ed Zschau. I want to thank these gentlemen for their leadership and interest.

For many years it has been apparent to persons with sensory and communication impairments, to their families, to their advocates, and to the professionals who work with this population, that sensory and communication aids and devices are not being disseminated to the people who need them. As a result, opportunities for meaningful education, worthwhile employment, and self-sustaining independence are being lost for many in this population. For a brief time, when available sophisticated technology coincided with available program funds under the vocational rehabilitation system and through the social security beneficiary rehabilitation programs, aids and devices often were provided to those who needed them.

However, as budget constraints increased, vocational rehabilitation counselors could not afford to put sizable amounts of case service money into aids and devices. At the same time, trust fund and general revenue dollars for the social security rehabilitation programs, both SSDI and SSI, dwindled to almost nothing.

Recognizing the problem, deliberations were undertaken on several fronts by experts in disability. One of these involved a consortium of manufacturers of aids and devices, of which my company is a part. Another was the evolution of an Office of Technology Assessment study entitled "Technology and Handicapped People." The study was requested by the House Science and Technology Committee and the Senate Committee on Labor and Human Resources. The result was a comprehensive analysis of programs and policies affecting handicapped people in this country, a thoughtful set of conclusions about those programs and the need for diffusion of technology to people with disabilities, and a number of actions to be considered by the Congress and the executive branch.

One of the major issues discussed in the OTA report was the means for reducing, within reasonable constraints, the financial barriers to the acquisition of technologies by disabled people. It is well worth citing at this point a statement on that issue contained in the report:

> Despite eligibility for the public and nonpublic programs that may pay for technologies to assist them to function more independently and productively, a number of disabled people are denied funding for particular technologies that are clearly appropriate . . . a primary reason for the denial of funding—especially under Medicare and Medicaid, but also other programs—is that the technologies in question are not strictly "medical" in nature and are therefore not considered "necessary." A connection needs to be made in these programs between paying for these technologies and the potential independence or productivity of disabled people.

The report also states that:

> OTA finds that disabled people with enough resources to prevent their participation in programs that pay for technologies also face serious financial barriers to technology acquisition. There are few available methods for financing the capital outlays that are often necessary, and those few that exist are available only in selected parts of the country.

OTA notes that under the current system of reimbursement in the Federal health insurance programs:

> In the short term, funds may be saved, while in the long term, a greater amount of total funds is expended in, for example, income maintenance payments or institutionalization expenses . . . the current system provides incentives for the dependence of disabled people on public programs. Changes enacted should provide incentives for independence.

Mr. Chairman, that statement brings me to the main issue in this hearing: Whether H.R. 4437 will provide incentives for independence for people with disabilities, and whether the cost of providing technologies is likely to be offset, or perhaps far exceeded, by the benefit accruing from the improved education, productiveness, and independence generated by the availability and use of sensory and communication aids and devices by people with disabilities.

Those of us who appear in this panel today, and many organizations and individuals across the country believe strongly that the answer to both questions is indisputably yes.

H.R. 4437 proposes to accelerate the dissemination of sensory and communication aids through the mechanism of medicare and medicaid. Some such devices are now being provided under these programs, but there is no clear national legislative or administrative policy for doing so. As a result, people with sensory and communication impairments, and the professionals who work with them, have no assurance that a needed device will be provided. Frequently the disabled person must undergo a lengthy appeals process after reimbursement is denied. There is no confidence that after being put through this process the cost of the sensory or communication aid will finally be allowed. H.R. 4437 will take away much of the uncertainty and delay now widely experienced by people who need this equipment to work, learn, and live independently.

H.R. 4437 is designed to restore parity for people who are blind and severely visually impaired, profoundly hearing impaired, and severely speech impaired in the medicare and medicaid programs which already reimburse the cost of prosthetic devices and wheelchairs as medically necessary. The theory of medicare, for example, in providing an artificial larynx to a laryngectomee, is to replace an internal organ lost through disease or accident. The theory has the same application in fitting an amputee with an artificial limb and training him in its use. The same theory should be used to provide sensory and communication aids, for these aids reduce or eliminate functional losses resulting from blindness, deafness, and the inability to speak. A stroke victim, a man who has had his larynx surgically removed because of cancer, and a person with severe cerebral palsy, may have deficits that are virtually identical: they are unable to communicate vocally. There is no readily discernable rationale for providing to one of these disabled persons equipment which will erase the physical deficit, while refusing to supply it to another.

Mr. Chairman, the need for this legislation is manifestly great. There is substantial national interest in H.R. 4437 and its Senate companion, S. 1115. We have heard from hundreds of professionals, consumers, and disabled organizations throughout the country who have ardently expressed the importance of these bills.

Mr. Chairman, I ask that representative letters and endorsements of S. 1115, the companion Senate bill, and H.R. 4437 be included in the hearing record.

Mr. MATSUI. Without objection.

Mr. BLISS. I know the Congress is under extreme pressure to pare the Federal budget deficit. It appears that H.R. 4437 is an effort to swim against a very strong tide. Senator Bob Dole, the chairman of the Senate Finance Committee, has expressed interest in this legislation but insists on caution. He wants to know the actual number of persons who would be eligible for the devices, their cost, and the estimated revenue from payroll taxes and lower welfare costs. He wants to be assured, if possible, that this legislation would reduce, rather than increase, costs.

Senator Dole's very valid concerns go to the heart of whether H.R. 4437 and S. 1115 can and should be enacted. Based upon our research and the accumulation and analysis of data on the potential eligible population, projected cost of aids, and offsetting benefits, we believe we can demonstrate that the bill would result in an economic benefit to the nation as well as independence for disabled Americans. Attached as an appendix to my testimony is a cost-benefit analysis of S. 1115, the companion Senate bill, as it applies to the medicare program. We believe our assumptions in this analysis are sound and that we have erred, if at all, on the conservative side in determining benefit levels.

It should be noted that the data available for this analysis are couched in terms of medicare recipients who are at or below the poverty level, and that employment is the criterion used to determine cost-benefit. At the same time, as with any projection, there are uncontrolled variables that should be kept in mind. Unanticipated events, such as a reversal of the current economic recovery, deterioration of international financial stability, or any of a plethora of possibilities, would affect the assumptions we have made.

To summarize the conclusions we have reached on the cost-benefit of H.R. 4437, we believe that the potential eligible population who would be in the education process or employable and receive aids would be approximately 36,000 people. The total annual cost of aids and devices to be acquired by or for this population is less than $22 million, assuming the program is fully operational and there is complete awareness among the target population. It is clear that some startup time for full implementation of the provisions of H.R. 4437 will be needed. Thus the first possible full year of operation would be 1985. The largest expenditure could possibly be in 1986 or 1987, but more likely later because of startup delays. Once the bulk of aids and devices are acquired and in use subsequent years expenditures would drop dramatically since the incidence of newly disabled persons with sensory and communication impairments is not large, and these aids for the most part have a relatively long useful life.

We project that the benefit in dollar terms resulting from H.R. 4437, on an annual basis, will be about $37 million. This amount is broken down as follows: $10.7 million in reduced welfare payments; $5.4 million in new tax revenues; $15.6 million in reduced social security disability benefits due to terminations; $5.3 million in reduced medicare costs. It should be pointed out that these benefit

amounts will continue year after year, and in fact increase because of inflation and improved earnings.

In addition to the benefits enumerated above, second and third tier economic benefits will accrue as a result of better educational and vocational development of young people, freeing family members for productive gainful employment, increased discretionary income expenditures and investments, and reduction of collateral program costs such as institutional care, social services, and rehabilitation services. Suffice it to say that the benefits of H.R. 4437, both short and long range, will be substantial, in both economic and human terms.

In conclusion, I believe the most important action that can be taken is to create a market for technology for handicapped people. This will increase the probability that technologies will reach the people who need and desire them, the number one issue discussed in the OTA report. By creating such a market normal economic forces will produce the most effective technology and delivery systems without excessive bureaucracy and administration. The Federal Government should play a key role in creating this market because numerous studies have shown that the application of technology by handicapped people is cost effective in savings to federally funded welfare and income maintenance programs.

The most effective way the Federal Government can create a market is by enabling disabled people or their parents to have the purchasing power necessary for the aids. This involves the consumers directly in the delivery system process, the second issue discussed in the OTA report.

Mr. Chairman, I urge you and the members of this committee to take favorable action on H.R. 4437, and to advocate for its passage in the House and Senate, and enactment into law. My colleagues and I will be pleased to answer any questions the committee may have.

[Attachments to the prepared statement follow:]

COST BENEFIT ANALYSIS OF S. 1115

Based upon a variety of data sources[1] the number of legally blind, profoundly and severely hearing impaired, and severely vocally impaired persons who are enrolled in Medicare, and whose family incomes are at or below the poverty level is 81,300. Of this number, about half, or 40,650 would not be appropriate candidates for employment because of age, severity of disability, or motivation. Assuming that only 10 percent of these persons currently have sensory communication aids available to them, the target population for providing aids covered by S. 1115 would be about 35,600. This is the number that would have the potential for gainful employment. In each year, about 30 percent of this number, or 10,700 could reasonably expect to receive the aids.

If 80 percent of the average allowable cost of sensory and communication aids is $2,000, the annual gross cost to Medicare under S. 1115 would be $21.4 million. This cost can be expected to drop substantially after the third year because the incidence of the covered disabling conditions is not large.

Since the purpose and expectation of S. 1115 is to bring about a wider dissemination of assistive aids to severely handicapped individuals, resulting in independence and productive employment, there are major cost savings to be anticipated from the

[1] Sources.—(1) Digest of Data on Persons with Disabilities, Rehab. Group, Inc., for Congressional Research Service, Library of Congress, 1979; (2) 1978 Survey of Disability and Work, Office of Research and Statistic, Office of Policy, Social Security Administration, DHHS, 1982; and (3) Social Security Bulletin, Annual Statistical Supplement, 1981, Social Security Administration, DHHS 1983.

enactment of S. 1115, including reduced welfare payments, reduced SSDI payments, reduced Medicare payments, and increased Federal, State and local tax revenues.

If one makes the conservative assumption that only half those who receive aids will become productively employed at or above SGA, the following estimated economic benefits would be directly attributable to the S. 1115 program. It should be noted that the beneficiaries not only have a work history, but also that half the potential population has been screened out because of age, severity of disability, and lack of personal motivation.

Reduction in welfare payments (at $2,000)	$10,700,000
Reduction in SSDI payments (at $2,910)	15,568,500
Reduction in Medicare reimbursement (at $1,000)	5,350,000
Increase in Federal, State, local taxes (at $1,000)	5,350,000
Total annual benefit	36,968,500

In the first year of enactment of S. 1115 it can be assumed that no economic benefit will accrue because of the program. It is eminently reasonable, however, to assume that after one year of distribution of, and training in the use of, these aids and devices, half of the aids recipients will have found work at or above SGA. The most compelling and attractive aspect of this program is that the benefits will continue to accrue, year after year, while the cost can be expected to occur only once. Therefore the benefit is many times the cost.

By the end of the second year after enactment of S. 1115, then, its net positive economic benefit will be $15,568,500. By the end of the third year the benefit will be $31,137,000. Because all of the approximately 16,000 successful recipients will have received aids and become employed after the fourth year, the annnual benefit thereafter could be as high as $110,905,500 and possibly much more.

Because aids are covered as optional services under Medicaid in S. 1115, costs were impossible to estimate. It can be assumed, however, that benefits would accrue under that program as well, although they could not be expected to be as great as under Medicare because of the lack of work history of Medicaid/SSI recipients, the severity of disability encountered, and reduced motivation for productive employment.

Mr. MATSUI. Thank you very much, Mr. Bliss.

Mr. Cowley, would you like to speak?

STATEMENT OF TOM J. COWLEY, VICE CHAIRMAN, PHONIC EAR, INC.

Mr. COWLEY. Thank you very much.

I am Tom Cowley, vice chairman of Phonic Ear. We are a company that has pioneered the use of FM systems for hearing impaired and voice synthesizers for nonspeakers. I appreciate very much, Representative Matsui, you calling this hearing and listening to our concerns today.

Rather than spend a lot of time on the need, which I think is evident, or build on Jim Bliss' point concerning buying power, which is very important it seems to me to harvest the dollars that we are spending in R&D and harvest the dollars the Government is spending in R&D on prosthetic devices by creating a market, rather than talk on those two points, I would like to talk a little bit on a way forward as I see it concerning classification of these devices as medical, prosthetic devices.

Very briefly, there are 12 pairs of cranial nerves that feed into the brain system. Many we are familiar with. The first, the olfactory nerve for the sense of smell; the optic nerve for the sense of sight; acoustic nerve, nerve eight, for hearing; the vagus nerve, the tenth, involved in driving the voice box and is the nerve that is often impaired for a cerebral palsy or stroke victim, and they lose their ability to speak.

It seems to me that what we are talking about is modern electronics, microprocessors, computers being available to augment those deficits that maybe occur because of damage to the sensory communications system. These augmentative systems, of course, use bits of data, microprocessors, the whole electronic revolution that is occurring in computers can be made available to sensory disabled and deficit individuals.

Quite frankly, implantable options in these areas are long term. They are farther out. We really have at hand the use of external prosthetic devices today to make major improvements in the employability and quality of life of individuals who have these deficits. I believe historically third-party reimbursement, particularly government funding, has been very instrumental in both internal and external prosthetic devices, in the cardiovascular field, in the renal field, in the orthopedic field, in the nerve stimulation field, where we are beginning to sensitize units and other units used very successfully for reduction of pain, bone growth.

The question really is what are we going to do for that population Representative Brown and all of us have talked to that have sensory deficits? Alternative prosthetic devices are at hand. Quite frankly, right now the markets are not there that are being created. It seems to me that through medicaid and medicare coverage, which our House bill is addressing itself to, and a similar bill in the Senate, it will begin a movement in this direction where third-party reimbursement recognizes the ability for these people to benefit from current technology.

In conclusion, you should have three concerns I think as you move forward along that avenue. The first concern should be the numbers. Are you getting into something that is so many numbers that it is going to be unfeasible from a budgetary point of view? The numbers we have presented are very realistic, if not conservative, as Jim Bliss has said, as far as the severe, the profound needs. This is where we need to focus.

I think a second question that needs to be talked about is what is the definition of instruments? We don't want to get into so many instruments and so many areas that we are not really benefiting the people in a sensory disability point of view. It seems to me we can work with you on definition. But something along the lines of enhancement of either the primary sensory nerve system or utilization of an alternative or secondary nerve sensory system to replace that one that has been damaged would be a comfortable definition I think we could make a lot of progress with.

Finally and most importantly, what is the payback? I am confident the payback will be there both in children who come through our educational system that are significantly better prepared as they reach the teenage years and early 20s to take important parts within our world. We have a great number of highly motivated people with sensory disabilities. These people need our help and they need your help. I am confident that the payback will be there both for the adult population, employable population, and the young children who are in school who could miss a whole education.

We could miss a whole generation of these devices if we don't move at this time. For that reason I recommend your continuing

with these hearings and moving ahead with passage of House bill 4437.

Thank you very much.

[The prepared statement follows:]

STATEMENT OF TOM J. COWLEY, VICE CHAIRMAN, PHONIC EAR INC., MILL VALLEY, CALIF.

EXTERNAL PROSTHETIC TECHNOLOGY CAN PROVIDE A QUALITY OF LIFE FOR THE SENSORY DISABLED

There are twelve pairs of cranial nerves that attach to the under surface of the brain, mostly from the brain stem. Their fibers conduct impulses between the brain and various structures in the head, neck, thoracic and abdominal cavities. For instance:

Nerve and functions

I. Olfactory—Sense of smell.
II. Optic—Vision.
VII. Facial—Sense of taste.
VIII. Acoustic—Hearing/sense of balance.
X. Vagus—Sensations of throat, larynx voice production etc.

Proper sensory functioning requires three elements: (1) a receptor organ: eye, ear, nose, throat. (2) Nerve transmission system (selected examples above) and (3) reception in a cognitive area of the brain.

Many sensory disabilities will involve reduced or non-functioning of one system because of impairment to one or more elements of the particular system: vision, hearing, speech, etc. In many instances keeness of another sensory system increases to partially make up for the loss.

This represents our challenge; to harness modern electronics, computers and microprocessors to utilize these alternate channels of the sensory system as a prosthetic or substitute. In many ways computers, miniature electronics simulating nerve system functions (handling thousands of data bits in microseconds) can help establish prosthetic transmission of data to and from the brain.

Implantable prosthetics for sensory functions in most instances are not close to feasibility. Lack of third-party coverage discourages market establishment and commercial firm interest in external electronic sensory prosthetics. Potential occupational opportunity and quality of life improvement is thus denied the sensory disabled.

Prosthetic approaches (external and internal) properly funded have a long-standing history of life prolongation and improvement for individuals with cardiovascular, renal, orthopedic and other disabilities.

Isn't it time, through third-party coverage, with the potential of micro-electronics at hand, that we should allow the sensory disabled, many of whom have a lifetime ahead, the benefit of utilizing external prosthetic technology?

Subcommittee on Health
Committee on Ways and Means
U. S. House of Representatives

Hearing on H. R. 4437

The attached is a selection of letters written with reference to The Handicapped Assistance Act of 1983.

These are only a few of the many letters parents, professionals and educational centers wrote outlining the difficulties encountered in securing funding for Sensory Aids for the handicapped. These letters are from all parts of the United States .... covering all ages and various levels of handicapping conditions.

They provide a very clear insight into the difficulties and needs of the physically handicapped in the United States in their efforts to secure funding for Sensory Aids.

Anna C. Hofmann
Human Resources Coordinator

February 27, 1984

Phonic Ear Inc.
250 Camino Alto Mill Valley CA. 94941-1490 U.S.A. 415/383-4000 TELEX 172 164

20 October 1983

Honorable David Durenberger
United States Senate
Washington, D.C 20501

Dear Senator Durenberger:

I am writing to urge your support of Senate Bill S.1115 and to ask you to push for hearings on S.1115 during this Congressional session.

Passage of this bill will open locked doors to many handicapped individuals, improve their quality of life immeasurably and will, in many cases, result in cost savings to the government and to taxpayers as these individuals are enabled to become employable.

At present, the acquisition of devices and aids which are readily available on the market are not available to handicapped individuals because of the cost. Let's face it: most severely handicapped individuals are either indigent or so close to the poverty level that paying for a device or aid from personal funds is impossible - and will be so for the rest of their lives.

I speak from bitter experience. I have been active in organizations supporting the handicapped for over thirty years. I am personally involved in a private endeavor which obtains used electric typewriters, modifies them for handicapped indigent people and donates them to the individuals for their personal use. A small thing, but one that has opened means of communication to many who have been able for the first time to contact the world around them.

My son Pat is 32, a severely handicapped cerebral palsy quadraplegic athetoid. He is confined to a wheelchair. His motor controls are so badly affected that he has little use of his hands. He types on a specially modified typewriter - his speech is so badly impaired that this is his only means of communicating with the world outside him.

Yet, with all his problems, he wants to WORK. He never complains about his problems - only that he wants to WORK.

Pat attends the local sheltered workshop. Because of his disabilities, the jobs he can do are so few and his pace is so slow that his normal pay is around $6.00 a week. No complaint with the pay - it's piece work and he just can't work any faster.

The heartbreaking fact is that his I.Q. is 125+ ! The staff of the sheltered workshop many times has indicated that Pat would be quite capable of holding an inspection or supervisory position if he could only communicate verbally.

There are devices on the market now - voice synthesizers- that Pat can handle and that would allow him to verbally communicate with others. The most suitable device - called "Phonic Ear"- costs $3,000. There is no way he can raise this amount, regardless of the tremendous impact it would have on his life.

Pat is covered by CHAMPUS. CHAMPUS,however, does not cover communication devices.

Pat is covered by my employer with medical insurance through Blue Cross/Blue Shield. Blue Cross/.Blue Shield does not cover communication devices.

Pat receives SSI and has Medicaid. Medicaid does not cover communication devices.

I have sought other public and private funding on Pat's behalf. There is no source to assist him in obtaining this communication device which would mean so much.

I cite my son's example only as one of many who need the coverage which Senate Bill S.1115 would provide.

I have a parent's concern for my son. I see many such individuals who could be employable, and so I also have a taxpayer's concern when I urge your support of Senate Bill S.1115.

Thank you,

Arthur W. Hamilton
4924Bullitt Road
Greencastle, Pa. 17225

(717) 369-2818

bcc: Senators-
Matsunaga
Dole
Packwood
Heinz
Baucus
Bradley
Mitchell
Specter

Anna C. Mitchell - Phonic Ear

Walter & Regina Koldys
34 Harrison Street
Bridgeton, N.J. 08302
August 16, 1983
Re: S.1115

Honorable Bill Bradley
United States Senate
Washington, D.C. 20510

Dear Senator Bradley:

We are writing in regard to a bill introduced by Senator Matsunaga in April of this year, S.1115. As you know, this proposal would amend the Social Security Act to treat certain sensory and communication aids as medical and other health services, and also to secure coverage through Medicaid/Medicare.

Our son Kevin is 11 years old and has Spina Bifida. While he is a very bright child and a fast learner, he cannot speak. In January of 1981 we learned of a new device, "HandiVoice" which could speak for him. However at a cost of $2650. we could not afford it and went to Medicaid for assistance. Their refusal in April of 1981 on the basis that this was not a medical device and not medically necessary, was very frustrating for us all. Here was something that could give Kevin the ability to communicate with others, participate in school and be more independent, and it was unattainable. We finally received $2150. from our private insurance and requested only the balance from Medicaid in a court hearing in August of 1981. Their insistence that this was not a medical device, only a communications aid was very upsetting. After spending so many months trying to get HandiVoice and exhausting every other means available, it seemed we were up against a brick wall. Well, the judge decided in our favor and Kevin got his own HandiVoice.

We were fortunate, but we know there are others who need these services and are not able to get them. We strongly urge that hearings be held during this session of Congress on S.1115. The hardships so many people face could be alleviated with the passage of this bill and the opportunity for them to lead a productive life and be a functioning part of society could be realized.

Thank you,

Walter & Regina Koldys

Walter & Regina Koldys

ANDREA F. BLAU
CONSULTANT
NONSPEECH COMMUNICATION
4901 HENRY HUDSON PARKWAY
RIVERDALE, NEW YORK 10471

(212) 796-5890

Daniel Patrick Moynihan
United States Senate
Washington, D.C. 20510

August 16, 1983

Dear Senator Moynihan,

I am writing, in support of Senate Bill S.1115 - the proposed amendment to the Social Security Act advocating the treatment of certain sensory and communication aids as medical and other health services.

I have been working with physically impaired speech disabled individuals since the early 1970s. During the past decade there have been tremendous strides in providing these individuals with mthods for communicating with others and becoming more independent members of our society. While in the early 70s there were few technological devices which could assist these individuals in overcoming their disabilities, today, with the advances in technology there are a range of sophisticated sensory and communication aids. No matter how severely physically disabled, an individual can now access a communication aid. Even a small muscle movement can serve as an interface to technology!

Perhaps the most exciting group of individuals I have worked with are the young physically impaired speech disabled children. Working with children below the age of three and using technology to help them compensate for their disabilities so that by age five or six they can be mainstreamed into the public school system, has brought the clearest examples of the importance of technology for the disabled. The time and expenses devoted to these individuals have both short term and long term benefits. Both the quality of life afforded to these individuals has improved and, with the increased independence available to them through the use of technology, their ability to take their place in competitive employment has surfaced.

The problem which still remains, is the inaccessibility of sensory and communication aids to numerous individuals who could benefit from their use but who can not afford to purchase these devices. Governmental support, such as that suggested by S.1115, would serve to guide Federal and State agencies in supporting the payments of such aids for all individuals who would benefit from their use. I urge you to help pass S.1115 into law!

Sincerely,

Andrea F. Blau

DONNA DeSHAW, M.A., C.C.C. - SP
Speech-Language Pathologist
1215 North Adams Street
CARROLL, IOWA 51401

(712) 792-1265

July 27, 1983

Honorable David Durenberger, Chairman
Subcommittee on Health, Committee on Finance
United States Senate
Washington, D.C. 20510

Re: Senate File 1115

Dear Senator Durenberger,

I am a speech pathologist in private practice in Carroll, Iowa. In that capacity I serve hospitals, nursing homes, a skilled nursing facility, sheltered workshops, and a residential facility for the handicapped. Those facilities serve patients who have cerebral palsy, strokes, head trauma, multiple sclerosis, and amyotrophic lateral sclerosis. All of these conditions may cause patients not to be able to speak well enough to communicate. In recent years, a variety of augmentative communication aids have been developed which allow such patients to communicate with their families and/or caretakers. Imagine my frustration as a professional trained to help develop a patient's use of an augmentative communication system, and the outright depression of my patients, when use of such systems cannot occur because Medicare and Medicaid deny such devices as "convenience items." The reading I have done of patient accounts, and the comments I get from families, both indicate that communication impairment is ever more devastating than physical impairment. Yet in reviewing Medicare guidelines I see where all manner of braces, wheelchairs, even hearing aids are covered, while communication devices are not.

I am currently awaiting the ruling on a second appeal I made to Medicaid here in Iowa on behalf of a young cerebral palsied woman I work with. She resides in a residential facility and has had serious behavior problems as a result of her inability to communicate. Medicare guidelines which list speech devices as "convenience items" were cited as the statutory reason her request was denied. She is an orphan and has no family to purchase the device she needs. With a communication device, she has the potential for consideration of placement in a less structured environment, but without such a device she is doomed to her present frustrating situation.

In my practice, I feel the need to have communication devices immediately available for patients in the hospital setting. When I inquired about the likelihood of insurance coverage for rental or purchase of such devices, I was informed that private insurance frequently parallels Medicare guidelines. My speech colleagues in the hospital setting tell me they must caution patients and families that coverage of communication devices is very uncertain.

34-346 O—84——3

I enclose two copies of information for your reference. The first is an article written by a person who has such a communication device, the second is a case study outlining the use of normal communication devices for a man with amyotrophic lateral sclerosis.

On behalf of my patients, their families, and the staffs who need to communicate with them, I respectfully request that you hold a hearing on Senate File 1115 during this session of Congress.

Respectfully,

Donna DeShaw

Donna DeShaw, M.A., C.C.C.-Sp.
Speech/Language Pathologist

dd/jep

The Marin Community Colleges
Kentfield, Calif. 94904
(415) 457-8811

December 15, 1983

Senator Dave Duremburger
Room 375
Senate Russell Office Building
Washington D.C. 20510

Dear Senator Duremburger:

I am writing you to encourage you to continue your support for Bill #4437 House and 1115 Senate. (Communication Aides for the Disabled)

I have worked in the field of Rehabilitation for 13 years, first as a counselor, now as a Coordinator/Fund Raiser for a large program for the Disabled at the community's College of Marin in California.

I met with one of your aides on December 2nd, and spent 20 minutes giving her details of the situation. She was professional, delightful and carefully ferreted out information you should have.

Basically, the disabled individual needs equipment to normalize their everyday life. They may use the equipment in classes they are enrolled in, for job training, or for maintaining their optimum physical and mental health so that they will not be a burden on their family, their community and our welfare rolls.

The bill supports the purchase of communication devices and medical equipment and is a step in the right direction. It will make what is needed to better a disabled individual's life more possible to obtain. I think we all conveniently forget that at present one out of ten Americans has a disability condition. Often it is hidden such as a hearing loss which requires the use of a communication device. Also it has been proven that almost all Americans will become at least temporarily disabled, and probably sustain a permanent disabling condition before they die. We are living to be older but not always in perfect health.

Fortunately, the technology exists in the United States to develop aids and devices to assist all types and severity of disabilities. With more funds available to purchase these devices (everything from phonic ears to talking

Wheelchairs, to robots to do tasks a disabled person cannot do), the world of a disabled individual will improve.

Thank you for your time and attention. Please carry forth these and other bills in the future that support optimum health and independent living for the disabled.

Feel free to contact me for more information.

Sincerely,

Lise S. Spielman

Lise S. Spielman
Coordinator, Disabled Students Program
College of Marin
Master of Science, Rehabilitation Counseling

cc: Robert Humpreys
Barbara Boxer
Anna Hoffman, Phonic Ear ✓

JANICE L. PETERSON, M.D.
PHYSICAL MEDICINE AND REHABILITATION
ELECTROMYOGRAPHY

1530 N. 115TH ST.
SEATTLE, WASH. 98133-8470

MEDICAL ARTS BUILDING
TELEPHONE 364-8181

November 7, 1983

The Honorable David Durenberger
Chairman, Subcommittee on Health
United States Senate
Washington D.C. 20510

Dear Senator Durenberger:

I am writing this letter in support of Senate Bill S. 1115, the "Handicapped Independence Act of 1983". I am a physician specializing in Rehabilitation Medicine and one of my roles over the past four years has been rehabilitation medicine consultation to the cerebral palsy clinic at Children's Orthopedic Hospital here in Seattle. During that time I have worked with a large number of children of various ages who are nonvocal due to cerebral palsy. Many of these children also cannot communicate by other means such as writing or pointing to picture boards because of their muscle control problems related to cerebral palsy. Technological advances have allowed even many of the most severely involved children and young adults to use one of the available pieces of equipment as a "speech prosthesis". When the have had this type of equipment available to use in the home and school setting it has had a very positive impact on their social and psychological adjustment as well as allowing them a means of demonstrating the knowledge which they have gained and which ultimately in some of them could lead to employment opportunities in the future.

As a physician, it is also extremely medically helpful for the nonverbal children to have a means of communication available to them. At this hopsital there have been two situations within the recent past where nonvocal children died in situations which normally would not have been life threatening had they been able to better communicate with their caretakers and the medical personnel involved. I was not directly involved in these two situations but have in many other situations encountered children who were clearly having discomfort and finding myself very frustrated in attempting to diagnose the cause of this discomfort because of the child's inability to provide more specific information. There have been a number of situations in which surgery was prescribed to deal with the medical impression of what was causing discomfort. In those situations it would have been easier to objectively weigh the potential benefits of surgery had a better communication system existed with the child.

There are certainly some of the children in this population with cerebral palsy who are cognitively not able to benefit from the best of technology available. On the other hand there are many of these children and young adults who I feel certain would have a much higher quality of life, be more productive contributors to society, and would receive better medical care

if they had improved communication systems. It has been my experience that it is very difficult to get this type of equipment funded through the traditional medical equipment funding sources. In many situations it has been viewed as educational equipment rather than something essential to the whole of a child's life. Certainly it would be an important asset to education just as the normal child's voice and ability to communicate is an important part of their educational experience.

I am very hopeful that this Senate bill will receive the support it needs to be implemented in order to make access to this important equipment more readily available to those who so definitely need it. I foresee that this equipment would be very cost effective overall as well. I can potentially see a number of situations where it could save medical costs by allowing more clear, concise diagnoses of problems based upon historical information and less reliance on test results. I also believe that it will ease the level of care needed by many of these disabled individuals by allowing them to more clearly communicate their needs to their caretakers and the best means of approaching these needs. Finally there is a population of these disabled individuals who could be employed contributors to society who would not otherwise be without an effective communication system.

Thank you for the interest that you and your subcommittee have shown in support of this bill.

Sincerely yours,

Janice Peterson, M.D.

cc: Anna Hofmann,
Market Analyst, Phonic Ear, Inc.
250 Camino Alto
Mill Valley, CA 94941-1490

Myra Isaman

Rehabilitation Institute of Chicago

345 East Superior Street, Chicago, Illinois 60611, (312) 649-6000 Writer's direct dial number
Accredited for Professional Services in Speech-Language Pathology and Audiology
American Speech-Language-Hearing Association

June 27, 1983

Honorable Senator Dole
United States Senate
Washington, D.C. 20510

Dear Senator Dole:

As professionals in the field of rehabilitation, we have recently become aware of the introduction of an amendment to the Social Security Act, proposed by Senator Matsunaga of Hawaii. This amendment (Bill S. 1115) is designed to treat certain sensory and communication aids as medical and other health services and to secure Medicare/Medicaid coverage for the purchase of these devices for disabled individuals truly in need of these types of equipment.

We are writing to request that you give serious consideration to the passage of this bill for the reasons that we have outlined below. After receiving this information, we hope you will understand the importance of communication aids and other adaptive equipment in the total rehabilitation of our clients.

I. Statistics: First of all, we want you to be aware of the number of requests we have sent to Medicare, Medicaid and other state and local resources for financial coverage of recommended communication aids and environmental control units for clients that have been denied. The table below shows that a significant percentage have been denied:

TABLE I

1980 - 1983

	Recommended & Submitted	Denied	Denied%
Communication aids	31	27	87%
Environmental Control Systems	38	36	95%

In the majority of these cases, the reason for the denial for providing the funds to purchase the equipment was that the item recommended was not a medical necessity. When these decisions were appealed, the same reason was given. We hope to refute this type of reasoning by stating that if a communicatively impaired and severely physically disabled individual without speech is unable to express pain, hunger, thirst, or other basic needs without some form of communication aid, then that individual is relegated to existing as a

vegetable. There is no other way for many of our nonverbal clients to ask for medical or physical help, to state their discomfort, to express their feelings, and ideas unless they have an alternate form of communication which will give them the opportunity to express themselves.

Similarly affected are those severely disabled individuals that may need a type of environmental control unit to enable them to place emergency phone calls in a medical crisis, to control a buzzer to ask for medical or physical assistance, or to control the power on a typewriter or computer that may enhance their potential to become employed, self-supporting members of our society. Because this equipment is not viewed as a "medical necessity", these individuals are denied the chance to be semi-independent, productive persons.

Just so that you have a clearer understanding of the population we are discussing, our clients fall into the following etiological groups: cerebral palsy, spinal cord injury, head trauma, stroke, brain tumors, cancer, multiple sclerosis, and other progressive and nonprogressive neurological disorders. Our program at the Rehabilitation Institute of Chicago is entitled the Brown Center for Alternate Communication and Environmental Control. Individuals referred to the Center are evaluated and trained in the use of various forms of communication devices/systems as well as environmental control units and other electronic adaptive equipment.

II Cost Effectiveness of Technical Aids: In order to highlight the cost effectiveness of these various devices, the following examples are provided:

A) A severely disabled, nonverbal child in the public school system requires approximately three hours of one-to-one assistance from a teacher's assistant who is paid $8.50 an hour. If that child had an electronic communication aid with memory and print-out capabilities, she could be set up with her own classroom assignments to complete independently, thus freeing the teacher's assistant for other children or other responsibilities. The communication aid would pay for itself in 148 days. ($8.50/hr x 3 hrs/day = $25.50/day). The cost of the device is $3780.00 ÷ $25.50/day = 148 days. It would pay for itself in approximately ½ of the school year -- 290 days. And, in an entire school year, the school would save $7395.00 in terms of the direct one-to-one assistance needed for that one child ($25.50/day x 290 school days per year = $7395,00).

B) A severely physically disabled young woman who is unable to use her head or arms for functional tasks is entirely dependent on another individual to control her environment. Use of an environmental control unit would enable her to operate electric devices, an emergency call system, as well as a telephone.

The Micro Dec Environmental Control Unit will enable her to remain at home for four hours at a time at least twice a day without attendant care. At a rate of $4.50/hour for attendant care (the maximum amount paid by the Department of Rehabilitation Services), this system will pay for itself in less than three months ($4.50/hour x 8 hours/day = $36.00/day). The cost of the environmental control unit is $2500.00 ÷ $36.00/day = 70 days. In one year's time, purchase of the Micro Dec Environmental Control Unit will save the funding sources $13,140.00 ($36.00/day x 365 days/year = $13,140.00 per year).

III Impact of Denial: The impact of denial for this type of equipment is all encompassing. Major areas affected include:

1) Attendant care - This equipment would enable an individual to communicate and/or stay alone for a limited number of hours per day by providing access to a telephone or buzzer in case of emergency. Absence of this equipment would entail either the higher cost of paying for attendant care or the necessity of a family member missing work or school to care for the disabled individual.

2) Financial Concerns - Occasionally individuals or families are forced to pay for this equipment. However, to purchase it they are forced to spend money required for other necessities.

3) Disruption of lifestyle - This impacts not only on the disabled individual but on his family and community as well. Vocational and avocational activities are likewise affected.

4) Dependency - By removing any possible means of communication or control, physical and emotional dependency is reinforced in the disabled individual.

5) Human dignity - Being physically dependent on other individuals to control his environment or communicate is a severe blow to any individual's self esteem. Provision of a means of control or communication provides the disabled individual with feelings of selfworth and dignity.

Your assistance in passing Bill S. 1115 would be sincerely appreciated.

Sincerely,

Jerri Voda, M.S.,CCC-SP
Senior Speech-Language Pathologist

Ruth E. Gordon, OTR
Senior Occupational Therapist

Courage Center
3915 Golden Valley Road • Golden Valley, Minnesota 55422 • (612) 588-0811

August 2, 1983

Honorable David Durenberger
United States Senate
Washington, D.C. 20510

Dear Senator Durenberger:

I urge you to recognize the importance of the passage of Bill S.1115 and to hold hearings for this bill during this session of Congress.

It's time that communication aids be recognized for what they are - medically necessary prosthetic devices that are essential in providing handicapped patients with the opportunity to meet their full potential to communicate, to function, and to be independent.

Many of our patients have been denied Medicare funding because communication aids are not considered medically necessary. This is absurd when one realizes that the device usually provides the patient with his/her only means to communicate even basic needs, medical requests to caregivers, and any other assistance he/she may need.

It is ironic that the very government that provides monies to promote research and development of new technologies for the handicapped deny patients that very opportunity by withholding Medicare funding for those devices that are desperately needed to restore patient to his optimal level of functioning.

Accordingly, I urge you to acknowledge the inadequacies of Medicare funding and include communication aids as medically necessary prosthetic devices.

Sincerely,

Peggy Dominic

Peggy Dominic
Hearing and Speech Assistant
PD/jn 8/2/83

Courage Center is a nonprofit organization providing rehabilitation, recreation, sports, camping, education programs and services for children and adults with disabilities.

STATE OF TENNESSEE

DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION

Greene Valley Developmental Center

P. O. Box 3087
Greeneville, Tennessee 37743

Office of the Superintendent

Telephone (615) 639-2131

May 27, 1983

Honorable Robert Dole
United States Senate
Washington, D.C. 20510

Dear Senator Dole:

We write to support Bill S. 1115 and the importance of providing Medicare/Medicaid coverage for communication devices and other sensory aids.

Staff at our facility work with individuals whose intellect and comprehension of language far exceeds their ability to communicate their understanding and to express their needs. One young man uses his eyes to answer questions which are phrased in such a way that his response can be movement of his eyes to convey yes or no. He's able to answer yes or no appropriately when asked. For example, if asked if he needs to use the bathroom, he can move his eyes appropriately. However, if his bathroom need occurs off schedule, he's unable to independently communicate this need to others because he's dependent on someone first asking him a question. A communication device would allow him to initiate a message such as "I need to use the bathroom" rather than his being dependent only on responding.

There are individuals who without communication devices will continue to be a brain trapped in a body. As communication is one of the unique characteristics and skills which distinguish humans from other animal forms, it is important that every opportunity be given to those whose bodies don't allow them the opportunity to communicate without the aid of an augmentative device. For some individuals it will allow not only greater enjoyment of life through social interactions but will be an important step toward vocational objectives.

We encourage you to seriously consider the value of this Bill.

Sincerely,

Doris H. Shelton, Ph.D.

Doris H. Shelton, Ph.D.
Director of Speech and Hearing

ks

cerebral palsy
center for the disabled
314 so. manning blvd.
albany, n.y. 12208
(518) 489-8336

AFFILIATIONS
ST. PETER'S HOSPITAL — ALBANY MEDICAL CENTER HOSPITAL
ALBANY MEDICAL COLLEGE
COLLEGE OF ST. ROSE — MARIA COLLEGE — RUSSELL SAGE COLLEGE
HUDSON-MOHAWK COMMUNITY COLLEGE — STATE UNIVERSITY OF NEW YORK AT ALBANY
UTICA COLLEGE OF SYRACUSE UNIVERSITY
UPSTATE MEDICAL COLLEGE AT SYRACUSE

President/Executive Director
Gerald B. Fitzgerald

Medical Director
Edwin L. Rosenblum, M.D.

PROGRAMS
Community Residence (4)
Day Training
Day Treatment
Education — School Age
Infant Pre-School
Out Client
School District
Home Service
(Ellis Major Project)
Pre-Vocational
Respite Recreation
Student Intern
Sheltered Employment
Vocational Rehabilitation
MEDICAL SERVICES
Diagnostic Services
Consultant Services
Audiology
Ear, Nose, Throat
Hand
Neurology
Ophthalmology
Orthopedics
Pediatrics
Physiatry
Psychiatry
Urology
SERVICES
Adapted Equipment
Biomedical Engineering
Client & Family Services
Commercial Contract Services
Dental Treatment
Nursing
Psychological
Regional Assessment
Therapies
Occupational
Physical
Speech
Transportation
DEVELOPMENT

September 14, 1983

Honorable Daniel Patrick Moynihan
United States Senate
Washington, D.C. 20510

Dear Senator Moynihan:

Currently there is a Senate Bill S. 1115 that is due to be discussed in the Senate Finance Committee. This is a proposed amendment to the Social Security Act to treat certain sensory and communication aids as medical and other health services. I would like to advocate the rights of those disabled persons, who have been denied the ability to communicate within their environment by urging you to support this Bill.

Communication is one of the essential components of life. The ability to communicate is a necessary prerequisite to success in education and to competitive employment. The availability and use of sensory and communication aids by the disabled population would have both short term and long term positive effects not only to a person's communicative skills and self esteem, but also on our nation's economy.

Communication aids are expensive to the point where it is beyond the financial means of most individuals. Those aids that are scanner boards or memo writers range between $500 to $6500. (Autocom-$6500). Those aids that contain a 'ce chip: and are much more efficient and useful because of not only the voice but also the auditory feedback necessary in communication, start at $2500. Although payment for such aids, equipment and devices is not expressly prohibited by statutes authorizing Federal health program, regulations of both Federal and State agencies result in widespread denials of such payments.

Within the field of education, reductions in the acquisition of sensory and communication devices for students in elementary and secondary schools has meant a set back for education and training for the individuals these aids can expediate the mainstreaming process by providing the necessary communication skills and by providing access to auditory and written information. If sensory and communication aids are provided to disabled children, in education environments when needed, most of the educable individuals could be trained to become productive wage earners upon completion of their education. These set backs therefore result in reduced entry into the labor market. Additionally, higher education, which had been secured with the aid of technological equipment, has already been threatened by funding reductions.

The inability to communicate stands between these individuals and competitive employment. Without these aids many individuals have to depend on welfare instead of competing for employment situations. It seems to me that in the long run to give these individuals the opportunity to work in the nation's job market and take them off welfare would reduce welfare costs while increasing tax liability.

I think that when reviewing these facts you will come to the same conclusions; to support this bill you would be giving the disabled person a better opportunity to communicate, and achieve concurrently with helping our nation's development and economy. Thank you for your concern.

Yours truly,

Nancy Gorman, MA-LSP
Senior Speech Pathologist

NG/clm

Humphrey
SBIC

Sensory Aids Foundation
399 Sherman Avenue Palo Alto Ca 94306 415 329-0130

August 9, 1983

The Honorable Senator Robert Dole
United States Senate
Washington, D.C. 20510

Dear Senator Dole:

The purpose of this letter is to express my support for government assistance in helping disabled persons secure sensory and communication aids for use in employment situations. Such technological devices offer to appropriately trained disabled persons the opportunity to be productive, independent, contributing members of society.

I enclose a short article which addresses the issue of cost effectiveness of government investment in independence oriented rehabilitation programs including investment in technological aids. Sensory Aids Foundation's Return On Investment report, described in this article, demonstrates the high return of such investment.

Thank you for your interest in this important issue.

Sincerely yours,

Marjorie W. Linvill
President, Board of Trustees

MWL:js

Enclosure

The Economics of Placing the Disabled in the Labor Market

By MARJORIE W. LINVILL
Sensory Aids Foundation, Palo Alto, California

While the human values of using technology to increase the disabled person's independence, self-esteem, and pride in productivity are important, focus on human values is not enough. High technology devices are expensive. It is necessary to demonstrate the cost effectiveness of government investment in independence-oriented rehabilitation programs, including investment in technological aids that facilitate productivity and independence.

Since 1975, more than 300 disabled people, primarily blind and partially sighted, have entered the competitive job market in California filling jobs previously not open to them. Using technology to provide disabled people access to a wide variety of jobs is a main goal of Sensory Aids Foundation (SAF), a non-profit corporation based in California.

The SAF employment development program, funded by Projects With Industry, CETA, the state of California, and private funds, is aimed at broadening the scope of employment opportunities for the disabled by applying sensory aids to specific job situations. Sensory aids are devices that strengthen or replace a sense that has been lost or diminished; such devices use both low and high technology.

We have compiled a report that serves as an example of productivity and financial responsibility. The report is based on statistics gathered for an employment development program that ended in September 1981.

The Return on Investment (ROI) is the ratio of income per year to investment required for the placement. The income is federal and state taxes and the reduction in government support. The investment is the equipment and costs of placement by Sensory Aids Foundation. This is the formula we use:

$$\text{TOTAL ROI} = \frac{\text{Reduction in Support} + \text{Federal Taxes} + \text{State Taxes}}{\text{SAF Employment Programs} + \text{Equipment Investment}} = \text{Return on Investment}$$

$$\text{TOTAL ROI} = \frac{\$141,540 + \$178,610 + \$14,530}{\$165,127 + \$145,555} = \frac{\$334,644}{\$310,682} = 107\%$$

Adapted from a speech to the National Institutes of Health Neural Prosthesis Workshop, October 14, 1982.

The reduction in welfare support and federal and state taxes are estimated for one year; sensory aids equipment costs are computed for each placement. If all welfare subsidy ceases at the time of employment, the ROI is 107 percent; if 50 percent of the welfare subsidy ceases at the time of employment, the ROI is 85 percent; and if welfare subsidy continues during the entire first year of employment, the ROI is 62 percent.

The SAF Return on Investment report was based on entry level employment, job retention, and job promotion activities. All of the people included in the report are severely disabled (28 totally blind, 25 legally blind, 1 deaf/blind, and 1 deaf). The average salary was $14,000, and the highest was $35,000. An informal survey done by SAF found that 43 of the 50 people (86 percent) are still working. The 14 percent who are not in their original jobs have left because of medical or emotional reasons, because they moved to another state, because it was a CETA job that has been discontinued, or because of dissatisfaction with some aspect of the job.

We are now preparing our 1982 ROI report. This year, the 60 people assisted will pay federal and social security taxes that equal 90 percent of the cost of SAF services and the total cost of sensory aids used. The gross annual earnings for these people is more than $750,000.

Let's look at an individual case to see specifically how return on investment works. One young blind man, after education and trials in different job areas, finally found the "right" job. He now works in personnel, a field usually considered too paper-oriented for a blind person. He must consult manuals and written documents and also write reports. He prefers to work with braille, so he uses a braille writer, a tape recorder, and a VersaBraille, a device that records braille on a tape cassette. All this equipment costs approximately $8,000. That is the same total as the federal and social security taxes the young man pays in one year, plus one year's total of welfare benefits saved because he no longer needs such assistance.

It is evident that even when expensive sensory aids are utilized in placement programs, such programs are cost effective to us as taxpayers and financially beneficial to the participants in such programs. These monetary figures are important, but they do not reflect the total value of such programs. The real value of such assistance still lies in the human values. □

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Carol Schneller
336 S. Palouse Street
Walla Walla, Washington
October 22, 1983

Honorable David Durenberger
United States Senate
Washington, D.C. 20510

I am writing concerning Senate Bill 1115. As a speech pathologist employed by a community hospital I would like to express the opinion that communication aids are a part of the health service provided to the patient for some patients. I am currently working with stroke patients and head trauma patients. Most of the time the patient will either improve verbal communication so that it is functional in the home environment or will be left severely impaired in communication. For a minority of patients a non-vocal aid will supplement the verbal and gestural skills that they have maintained. I have attended several professional conferences where we are reminded that research shows that non-vocal aids do not prohibit development of verbal communication but rather encourage patients to use their residual communication skills.

I have worked with several kinds of patients who have benefited from assistive devices. I have not had a great number of patients because of the diversity of the caseload I work with here and did work with at a children's diagnostic center.

One of the cerebral palsied children I worked with was learning to use a board which consist of hand made pictures on a format of 16. A light moves to designate the square of the picture. Panels of pictures can be changed so that the client pushes a switch to move the light to a designated panel. The board was funded through the state of Washington out of the boy's personal funds because the boy was a dependent of the state.

I have worked with head trauma patients who have lost either their oral language skills or their ability to phonate. The two people that I recommended devices for were younger people. In both cases private insurance companies were covering the health care. One of the companies purchased a device for their client. He was involved in a serious logging accident. The other health insurance company declined to fund a letter keyboard for a yound girl because it was not considered a durable medical good. I believe that her auto insurance company provided funds for it as general coverage of expenses incurred within a certain time of the accident. Some patients will need an assistive device for a certain period of time. Others will rely on one on a long term basis.

I would also like to comment that within the discipline of speech pathology the interest in non-vocal communication and assistive devices has been very strong over the last decade. The states of Washington and Oregon have been particularly active in forming an organization interested in non-vocal communication. Membership draws from the disciplines of physical therapy, occupational therapy, and speech pathology. Some of the manufacturers representatives also belong to the group and enjoy the opportunity to exchange research ideas. The group is called the Pacific Northwest Nonvocal Communication Group. There are chapters in Portland, Seattle and in eastern Washington. Nationwide of course there are several research centers that are making information about electronic devices freely available to us. Their interest is in research as well as in adapting equipment for particular clients' needs.

Families are ordinarily very eager to become involved in the process of selection of the format to accompany the device. This area of communication remediation is certainly a hopeful one for them. It is also encouraging to those of us who are working in the field of communication disorders because of the promise for people who otherwise would be isolated to various degrees in their communication.

I hope that the Senate would pass the amendment to treat certain sensory and communication aids as medical/health services. It would be very helpful for Medicare and Medicaid patients to have the communication products covered in their medical benefits.

Sincerely,

Carol Schneller

Carol Schneller
Speech Pathologist
St. Mary Community Hospital
Walla Walla, Washington

34-346 O—84——4

LAW OFFICES OF
EAST RIVER LEGAL SERVICES
329 North Phillips Avenue, Sioux Falls, South Dakota 57102-0306, Telephone (605) 336-9230

August 4, 1983

Also Sent to Senators Pressler
Abdnor
Daschle

Honorable David Durenburger
353 Russell Office Building
Washington, D.C. 20510

RE: Medicare funding for Dean Gellhaus

Dear Representative Durenburger:

I represent Mr. Dean Gellhaus in his attempt to obtain Medicare funding for a Handi-Voice speech prosthesis. Dean is twenty-five years old and is a resident of Sioux Falls, South Dakota. He contracted viral encephalitis at age seventeen and cannot speak.

The legal issues in this matter are whether the Handi-Voice is medically necessary for Dean and whether the device replaces "all or part of the function of a permanently inoperative body organ." The Handi-Voice is a portable electronic voice synthesizer that can communicate verbally any word in the English language. Dean is destitute, and the Handi-Voice costs over $2,700.00, so without assistance from Medicare Dean cannot hope to obtain the device. Dean has filed a claim with Medicare and twice been denied funding because Medicare regards the Handi-Voice as non-medical equipment.

Dean is a bright young man and enjoys writing. He has written short stories and is working on an autobiography. At present his only means of communication is a primitive board with words and letters printed on it. Dean points from word to word to formulate sentences. The process is laborious and often frustrating for Dean. The difficulties he has encountered in attempting to communicate have caused Dean increasingly to withdraw from society. His loneliness is profound.

It is the opinion of virtually every health care professional who has examined Dean that the Handi-Voice speech prosthesis is essential if Dean is to have the opportunity to lead a productive and happy life. Dr. Donald Barcome of Grand Forks, North Dakota wrote a prescription for a Handi-Voice for Dean in April, 1982. Yet Medicare has twice refused to assist Dean. The injustice of these refusals is manifest.

Please exert your influence in any way you can to see that Dean can obtain the Handi-Voice. Dean has requested a Medicare fair hearing on this issue, but I am concerned that without the intervention of an elected official Medicare will once again deny Dean's claim. Letters in support of Dean's cause should be sent to:

Fair Hearings Section
Medicare
P.O. Box 7968
San Francisco, CA 94120

In addition I urge that you support passage of S.1115, which was introduced by Senator Matsunaga on April 20, 1983. The bill is presently before the Subcommittee on Health. The bill would provide funding for "sensory and communication aids" for people who share Dean's plight.

I thank you in advance for your time and consideration. Please contact our office if you have questions about Dean or his disability.

Sincerely,

John Davis
Intern

JD:skb

Northeastern University

360 Huntington Avenue, Boston, Massachusetts 02115

Office of Services for the Handicapped
05 Ell Building
617-437-2675 (voice), 617-437-2730 (TTY)

November 21, 1983

Honorable David Durenberger
United States Senate
Washington, D.C. 20510

Dear Senator Durenberger:

We are writing to you to offer our support for S. 1115, the amendment to the Social Security Act which would treat some sensory and communication aids as health services payable by Medicare/Medicaid.

Because we work with disabled people every day at Northeastern University, we are aware of how critical it is for sensory-impaired people to have access to as much information as possible in order to achieve in the classroom.

We employ students to read to those who need assistance but, for several reasons, this is not entirely successful. First, it requires the coordination of schedules of a number of people who are under pressure to complete their own schoolwork. Students who are able to read their own materials have the opportunity to go over them several times, regardless of how many hours it takes. With a reader, this is rarely possible. Second, having material read by another person denies that individual the privacy we take for granted.

The cost of most equipment is prohibitive for the average person. Without governmental support the technology invented to help equalize the chances for the success of disabled people may be unusable.

Sincerely,

Karen Schneiderman
Craig Andersen
Georgi Morse
Arunas Kuncaitis
Liz Neault
Lee Kramer
Holly Ross
G. Ruth Kukiela Bork
Maureen Marinelli

July 1, 1983

Honorable David Durenberger
Chairman
Subcommittee on Health
Committee on Finance
United States Senate
Washington, D. C. 20510

Dear Dave:

I am writing in regard to my bill, S. 1115, which is designed to amend Titles XVIII and XIX of the Social Security Act. This measure, which I introduced on April 20, 1983, is now pending before the Committee on Finance. I would greatly appreciate your assistance in scheduling hearings on this bill at the earliest appropriate date.

As you know, S. 1115 would amend the Social Security Act to treat certain advanced sensory and communications aids as medical and other health services under Medicare. My bill would clarify current Medicaid provisions so that the states may provide coverage of these aids under their programs, but are not required to do so. Although payment for such aids, equipment, and devices is not expressly prohibited by statutes authorizing federal health insurance programs, regulations of both federal and state agencies have resulted in widespread denials of such payments.

By providing greater accessibility to these devices, which could allow severely visually, hearing, or vocally handicapped persons to compete in today's job market, many new employment opportunities would be opened. In addition, these sensory and communications aids would reduce the handicaps of such individuals with respect to education and self-care. The enactment of S. 1115 is necessary to make the individual purchase of such equipment feasible for disabled persons.

I am very hopeful that the Committee will address this measure in the near future, and would appreciate any assistance you might provide in scheduling a hearing

before the August recess or in the early fall. A separate hearing on S. 1115 would not be necessary. An hour for testimony on the bill from a panel, as part of a health hearing, would be sufficient.

Thank you very much for your attention to this matter.

Aloha and best wishes.

Sincerely,

Spark Matsunaga
U. S. Senator

Helen Keller National Center

For Deaf-Blind Youths and Adults

PETER J. SALMON, LL.D., Founder
MARTIN A. ADLER, MSW, ACSW, Director

operated by
THE INDUSTRIAL HOME FOR THE BLIND

May 3, 1983

The Honorable Spark M. Matsunaga
SH-109 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Matsunaga:

I am expressing interest and support in S. 1115, a bill to amend titles XVIII and XIX of the Social Security Act to treat certain sensory and communication aids as medical and other health services, and for other purposes.

Briefly, the Helen Keller National Center, as we indicate in our attached brochure, is the one national agency that provides services to deaf-blind youths and adults. One of our elements of service is in the research and development of technical aids and devices for deaf-blind individuals. We recently developed and have marketed a device that we call the Tactile Communicator. May I please refer your attention to the attached description of the Tactile Communicator. This device is being sold to deaf-blind individuals at a cost of $300 which, of course, does not account for research and development which span a number of years. It is important that we maintain a low cost in order to enable deaf-blind individuals to purchase the TC.

I was particularly impressed with your statements reflected in the Congressional Register regarding the importance and availability of sensory devices to aid the handicapped in seeking and maintaining employment. Although the TC costs only $300, many deaf-blind individuals who are on Social security disability insurance programs do not have the funds necessary to purchase this device which, at times, can be a life-saving instrument for them. We do hope that your bill, which would make sensory and communication devices more available through funds allocated by social security, will be successful.

If we can be of any further assistance to you, please let us know. We would certainly welcome an opportunity to show you our facility and our service delivery program at any time that you are in the New York area.

Sincerely,

Martin A. Adler, MSW, ACSW
Director

MAA:bf
Encl.

BC: Robert Humphreys
Gale Sokoloff (Congr. Mrazek's office)
Dean Wyrick
Connie Watters-Miles
Herb Cohen

HEADQUARTERS: 111 Middle Neck Road, Sands Point, N.Y. 11050 • Tel: (516) 944-8900 (TTY and voice)

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RESOLUTION 83-08

WHEREAS, sensory and communications aid , such as "talking" computer terminals, reading machines and large print displays are used by blind and disabled persons to gain or to advance in employment and education; and

WHEREAS, these devices as well as other sensory and communications aids which benefit persons with other disabilities are often so expensive that the majority of individuals cannot afford to purchase them; and

WHEREAS, funding sources for the purchase of sensory and communications aids are limited.

NOW, THEREFORE, BE IT RESOLVED by the American Council of the Blind in convention assembled on this 6th day of July, 1983 in Phoenix, Arizona, that this organization urges passage of Senate bill S. 1115, introduced in the 98th Congress, which provides for coverage of sensory and communications aids under the federal Medicare program and further, permits the individual states to reimburse for such equipment under state Medicaid programs; and

BE IT FURTHER RESOLVED that the officers, directors and staff of this organization shall communicate our support of this bill to the appropriate members of Congress.

CHILDREN'S ORTHOPEDIC HOSPITAL
AND MEDICAL CENTER
4800 Sand Point Way NE, P.O. Box C-5371
Seattle, Washington 98105
(206) 526-2000

UNIVERSITY OF WASHINGTON
School of Medicine
Department of Pediatrics, RD-20
Seattle, Washington 98195
(206) 543-3160

October 24, 1983

The Honorable David Durenberger
Chairman, Subcommittee on Health
United States Senate
Washington, D.C.
20510

Dear Dr. Durenberger:

This note is to indicate my strong support for Senate Bill S.1115, the "Handicapped Independence Act of 1983." I am responsible for running a large clinic that provides medical services to children with cerebral palsy and related disorders. Over the last five years I have seen the rapid growth of technology to the point where a "speech prosthesis" is now a viable option for almost any child who is nonvocal because of cerebral palsy. While some of these children have severe disabilities of other sorts that may impair learning, many of them have excellent potential that is stymied by their severe physical disability. With an independent means of communication, I have little doubt that some of these children are capable of competitive employment while many others will be less dependent and easier to care for because they will be able to communicate their needs more clearly.

I can state as a physician that it is particularly frustrating to try to provide acute medical care for an individual who is nonvocal. At our medical facility we have had at least two deaths that occurred because children could not communicate their symptoms. One had a treatable subdural hematoma (bleeding between the brain and the skull) and the other had appendicitis. Older individuals with communication problems often express their extreme fear and even panic of having to go to an emergency room where they will not be able to communicate with the personnel.

Medical insurance companies and government medical coverage programs have been quite reluctant to fund speech prosthesis and other communication equipment for children. This is particularly unfortunate given the fact that a child who has never had the chance to use language normally is at a greater handicap than an adult who secondarily acquires

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Developmental Disabilities Clinic
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Neuromuscular Clinic
[illegible], M.D., Chief

a deficit. We encountered this same reluctance to fund wheelchairs and other more sophisticated mobility equipment some years ago. It has now been demonstrated that mobility devices including power wheelchairs are quite effective and funding is less of a problem. Senate Bill S.1115 would be a valuable step forward in making speech prosthesis available to children.

My thanks to you and your subcommittee for pursuing this issue.

Sincerely yours,

John F. McLaughlin, M.D.
Director, Neuromuscular Clinic
COHMC

cc: Anna Hofmann, Market Analyst, Phonic Ear, Inc.
Myra Isaman, President; Pacific Northwest
" Nonvocal Communication Group
Peter Pulrang, M.D., Crippled Children's Services

JFM:cg

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Mary T. Ballard, Editor
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RESOLUTION 83-11

WHEREAS, high technology devices such as "talking" computer terminals, reading machines and closed-circuit magnification devices are used by blind and visually impaired persons to gain and to advance in employment and education; and

WHEREAS, such equipment is expensive and often is beyond the reach of many individuals; and

WHEREAS, alternative funding sources for this equipment are limited; and

WHEREAS, such equipment may materially enhance the upward job mobility and career potential of the blind and visually impaired persons who use such devices; and

WHEREAS, the Office of Technology Assessment has issued a report entitled Technology and the Handicapped, which outlines various ways in which technology can be made more readily available to handicapped persons including tax incentives, loan guarantees, and Medicare coverage for such equipment.

NOW, THEREFORE, BE IT RESOLVED by the American Council of the Blind in convention assembled on this 6th day of July, 1983 in Phoenix, Arizona, that this organization believes that access to technology is essential in order to maximize the education, employment, and independent living potential of blind and visually impaired persons; and

BE IT FURTHER RESOLVED that the officers, directors, and staff of this organization are hereby instructed to support and/or initiate statutes and regulations which will make technology more affordable and accessible to blind and other handicapped persons, with particular attention being given to the recommendations contained in the Office of Technology Assessment report.

Mr. MATSUI. Thank you, Mr. Cowley.
Mr. Romich.

STATEMENT OF BARRY ROMICH, PRESIDENT, PRENTKE ROMICH CO., SHREVE, OHIO

Mr. ROMICH. Yes; I am Barry Romich, president of Prentke Romich Co. Our business is small. It is that of helping people with severe physical disability and without speech to achieve their full potential through the use of technical aids.

Technology offers the people of our society the opportunity to reach levels of achievement never before possible. We all use machines for communication, transportation, entertainment, and in the performance of our jobs.

For people with physical handicaps, technical aids are also available to help them reach their goals in educational, vocational, and personal pursuits. However, these people are frequently denied access to these aids, the opportunities they offer and the levels of achievement they permit. This is because the cost of the aids and accompanying services is beyond their ability to pay.

The technical aid solutions to problems caused by physical disability can be expensive, although frequently a good investment, for many reasons. One reason is that the market is small. The need for technical aids is only a minute fraction of the market for consumer items.

However, it is further diminished because the per capita income of the physically disabled is far lower than that of the general population and they normally have many other expenses relating to the management of their disabilities. In addition, a technical aid alone does not solve the person's problems. The services of a rehabilitation professional are often needed in the selection and application of the appropriate technical aid.

The people who need these devices and services have few alternatives regarding funding. For some, private insurance coverage is available. A few others are clients of vocational rehabilitation agencies or are able to receive systems through the Veterans' Administration.

For some students, the public school may provide a system for use only while in the classroom. Some have resorted to public appeals through the media. A precious few have the necessary personal financial resources. Too often we find frustrated rehabilitation professionals are using their valuable time to look for funding rather than providing therapy.

Many of the people who need these devices find that no funding source is available to assist them. Rather than have their lives wasted, these people are looking to their government for help. For some of them, money spent for technical aids is a good financial investment. For others, the return is only the gift of life.

The industrial revolution is over. The information revolution is underway. It is here. For people with physical handicaps there has not been a better time in history. With the appropriate technical aids these people can have access to the tool of the information revolution, the computer. With that tool they can access, process and communicate information. They will be able to reach high levels of

achievement. Without that tool they will be a perpetual burden to our society. The time for action is now. I urge support of this legislation.

A measure of the strength of a society is the degree to which that society permits the least of its members to reach the highest possible levels of personal achievement. I would like to think that our society is that strong.

[A chart, "Features of Commercially Available Communication Aids," has been retained in the subcommittee files.]

Mr. MATSUI. Thank you very much.

At this time I would like to call David Crowley to testify.

STATEMENT OF DAVID CROWLEY, MANAGER, GOVERNMENTAL AND PUBLIC AFFAIRS, KURZWEIL COMPUTER PRODUCTS, CAMBRIDGE, MASS.

Mr. CROWLEY. Thank you.

My name is David Crowley, manager of Governmental and Public Affairs for Kurzweil Computer Products of Cambridge, Mass. We are a small manufacturer of a machine which applies artificial intelligence to optical character recognition and synthetic speech. This machine, known as the Kurzweil reading machine, enables blind and print-handicapped people to have direct and independent access to printed and typeset materials.

Traditionally there have been two issues associated with sensory aids for handicapped people. The first question revolved around how to develop the sophisticated equipment necessary to do the work of human organs and limbs. Now, with that question largely resolved, we must turn our attention to the second question, which is the lack of purchasing power of those people for whom the aids and devices are now being manufactured.

Congress has done a superb job in providing the leadership and resources necessary for the research and development of sensory aids for handicapped people. I too refer to the recent report by the Office of Technology Asssessment which concluded that while the research into the aids and devices must continue, there are now a wide assortment of sensory aids on the market and available to handicapped people.

We believe these aids are the best example of the application of American technology to human needs. But as the OTA report stressed, the challenge before us now is to get those aids into the hands of those who need them the most.

H.R. 4437 is a bill which addresses that important question.

Traditionally because of the limited access to educational and employment opportunities, as Oral Miller has previously pointed out, handicapped people have not had the economic resources to acquire such sophisticated equipment. We are here today to ask the committee to address this problem.

Having seen the fruits of the earlier research and development efforts demonstrated here prior to the hearing, we ask the committee to complete its work and now turn its attention to the important issue of assisting handicapped people to acquire the aids they need for a more full and productive life. We feel H.R. 4437 is an important step in that direction.

Thank you very much.

Mr. MATSUI. I would like to now call Guy Carbonneau.

STATEMENT OF KURT STEPPLINS, DIRECTOR OF MARKETING, TRIFORMATION SYSTEMS, INC., STUART, FLA.

Mr. STEPPLINS. Mr. Carbonneau was unable to attend. I am Kurt Stepplins, director of marketing for Triformation Systems. Our organization is in the manufacturing and marketing of sensory aid devices for the blind and visually impaired individual.

Fourteen years ago at that time, the primary source that a blind individual had to information was, as Mr. Miller referred to, either through audio means or through hard copy braille. At that time, companies such as ours at this table began springing up in existence and providing alternative means of informational access, if you will. In that time, our company alone is responsible for well over 50 percent of the braille materials in the world today.

Mr. Chairman, I ask you to consider for a second for a blind individual to have a Webster's Dictionary in their house to look at in print copy would take 64 volumes for a complete dictionary. Although that is more cost effective, it is rather impractical for a blind individual to have the same type of materials in their house as you and I do.

By the same token, devices such that are available today where that same dictionary can be put to a cassette or into a diskette made available through current technology allows for a greater access to information by the blind individual, although the devices themselves are more costly.

We invite the Government to join with us in a dual responsiblity we all share. That dual responsibility is on our part providing credibility and quality of goods that achieve the needs of the blind individual. On the Government's part it is to assist us to make this a realistic endeavor such that the blind individual is able to have access to these devices.

We have heard talk of increased employment and educational opportunities made available by these devices. Oftentimes the blind individual in cases where we are familiar, employment itself or advance within employment or education is tied to the use of these devices. Without them, the individual is caught in a vicious cycle.

We ask you to help us take that individual out of that vicious cycle and bring them to a level of mobility within our society that we all share.

The question that hasn't been addressed yet that is very important is, once an individual is employed, what is the reliability of that employee? Fifteen percent of our organization's work force are blind. In the past 3 years the absenteeism rate of that blind individual has been less than 1 percent. Their sighted colleagues have been running closer to 3 percent.

Through conversations with others at this panel, through professionals in the field, that statistic is borne out throughout the country, that the blind individual time in and time out is a much more reliable employee, lower absenteeism and greater proficiency in their work effort. They make very quality, reliable employees in that respect.

I would like to conclude my remarks with this, that is to invite you, Mr. Chairman, and members of the panel and fellow guests here today to all join in the responsibility we all share of bringing our level of technology that our country has developed down to the level where we are all able to share in it and not just a select few.

So I urge your support of H.R. 4437 and its passage through Congress and urge you to support the Senate companion bill.

Thank you.

Mr. MATSUI. Thank you very much.

Mr. Bernard Blasch.

STATEMENT OF BERNARD BLASCH, VICE PRESIDENT, SENSORY AIDS CORP., BENSENVILLE, ILL.

Mr. BLASCH. I am Bernard Blasch, vice president of Sensory Aids Corp. located in Bensenville, Ill. We are a small company that manufactures electronic aids for the visually impaired and totally blind. Two of our product lines concern the use of sonar devices for the totally blind person to negotiate and be more independent in his mobility skills.

Our newest product line includes the use of fiber optic scanning aids to enlarge printed matter for visually impaired individuals. One of our concerns is the visually impaired legally blind population can, dependent on availability, receive exposure and/or even instruction in the use of advanced technology to assist in dealing with the everyday activities we all face.

To a limited extent, these individuals learn to utilize these aids to enhance their quality of life. Because of the cost factor, however, all individuals are not capable of benefiting from the advanced technologies. The schools or agencies that own these devices only assist these people currently as far as the door to that facility. There is a pressing need to make these aids available for around-the-clock usage by these individuals.

The student who needs to do homework cannot, because his aid cannot leave the school property. Or upon graduation from school where he has become accustomed to the availability of this equipment, he sets off to face the world without this sensory aid, which he would have relied upon so heavily.

All these sensory aids can become an integral part of these people's lives and they can be essential to their employability in the future. We must do whatever possible to make these sensory and communication aids available to these individuals. Therefore, I wish to strongly urge support of H.R. 4437.

Mr. MATSUI. Thank you very much.

I would like to commend all six of you and your companies for using the technology we have today for assisting those that are handicapped. I think that what you are doing is extremely important and humanitarian. Hopefully, the Government will be able to give you the assistance and wherewithal you need so that you can continue to provide these kinds of opportunities for people that have for so long not had the opportunity to excel and grow in their own lives.

I would like to ask Mr. Moore if he has any questions.

Mr. MOORE. Mr. Chairman, no questions.

I too would simply like to join you in commending the tremendous technological advances that are being made in all sorts of devices such as this. I think we haven't begun to see the full extent or completion of that work. I certainly commend everybody involved.

Mr. MATSUI. Thank you again.

I know you are all here from all over the country, so I appreciate the fact that you flew in. Of course, it is snowing outside. But we hope you enjoy your stay here.

Mr. BLISS. Thank you.

Mr. MATSUI. I would also like to thank Paul Rettig and Karen Lloyd on the subcommittee staff for assisting Congressman Jacobs in putting this hearing together on a short notice. They were only asked to set this hearing up some 2 weeks ago. So we appreciate very much their efforts, of course.

We would like to call Morgan Downey and Carol Cohen to testify at this time. Without objection, your written testimony will be submitted for the record. You may, however, read or summarize your testimony.

I would like to at this time call Morgan Downey to testify.

STATEMENT OF MORGAN DOWNEY, DIRECTOR, GOVERNMENTAL AFFAIRS DEPARTMENT, AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Mr. DOWNEY. Thank you, Mr. Chairman.

I will try to summarize our testimony.

I am pleased to represent the American Speech-Language-Hearing Association, which is the national professional and scientific society for some 39,000 speech-language pathologists and audiologists, many of whom are actively providing services to medicare beneficiaries in acute care and rehabilitation hospitals, skilled nursing facilities, home health agencies, hospices, comprehensive outpatient rehabilitation facilities, and rehabilitation agencies.

We are very pleased to come today. I would like to just focus a bit on the impact of this legislation on the medicare system and the elderly population. I think it is clear from the preceding testimony that these devices are essential for many individuals with severe communication impairments and that, for a great number of citizens, the legislation under consideration would resolve their very difficult problems in daily living.

In terms of the medicare population, I would like to bring to your attention some of the projections that our association has developed. Currently for the medicare population some 20 percent suffer speech impairments and some 43 percent have impaired hearing.

However, the rates of these impairments are expected to increase dramatically in the next several years. We predict by the year 2000, a quarter of the medicare beneficiaries will have speech impairments and nearly 46 percent will have impaired hearing. By the year 2050, which I guess is approximately the time that a child born at this period would become eligible for medicare under the current requirements, some 40 percent of the medicare population

will have speech impairments and nearly 60 percent will have impaired hearing.

So we are dealing with a disability here that is acccelerating for the elderly population and is becoming more serious as the nature of the workforce and nature of our society changes. We are very pleased with your leadership and leadership of the other cosponsors for bringing this to the attention of your fellow members in Congress. We congratulate you and hope that you maintain this activity.

We do, however, have a few problems with the legislation currently under consideration. These problems are three. First, the legislation contains a cap on the cost of the devices to be reimbursed. While the limitation of $5,000 may be a very useful device in terms of urging the technological development to keep within that type of limit, we are concerned whether that would fully cover the costs of fitting and adapting the device itself, and the training that is needed to make sure that the device is useful and beneficial to the medicare beneficiary.

Second, we are concerned that the legislation does not include coverage of hearing aids. Under the proposed legislation, there is a certain ambiguity in terms that it does cover communication aids but it doesn't expressly repeal a prohibition in medicare against the reimbursement of hearing aids.

We would like to see the committee resolve this ambiguity clearly in favor of the coverage of hearing aids. This is the device probably most widely needed by the medicare population and one which should be included under this legislation.

Third, we are concerned the legislation would change the present delivery system for these devices. By assuming continuation of the current medicare practice requiring a physician prescription for these devices, the current manner in which these devices are provided will change. Speech-language pathologists and audiologists determine the need for these devices, select the most essential system for daily living.

We tend to agree with the report alluded to already by the Office of Technology Assessment which stated that physicians are unfamiliar with most communication devices and systems. This committee recognized in 1980 in the Omnibus Budget Reconciliation Act that speech pathology involves a highly specialized knowledge and training and physicians generally do not detail the services needed in particular.

So we would urge that in order to make sure this benefit, should it be enacted, is available to the bulk of communicatively impaired individuals that it would provide these devices upon prescription of either a physician or qualified speech-language pathologist or audiologist where appropriate.

I will conclude my remarks now by saying we believe that devices alone are not the total answer to the needs of this population. There are a great many ways in which medicare and, to some extent, medicaid can be improved in order to provide not only devices but access to qualified professional assistance. I have enumerated some of those reforms in my testimony.

Our association is very eager to cooperate with the committee in fashioning a legislation that will meet fully the needs of the com-

municatively impaired population, and we have tried in our testimony to provide a lot of data about this population and about the activities of our members regarding this population. We certainly stand ready to work further with the committee in any way we can.

[The prepared statement follows:]

STATEMENT OF MORGAN DOWNEY, DIRECTOR, GOVERNMENT AFFAIRS, AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

INTRODUCTION

The American Speech-Language-Hearing Association (ASHA) appreciates this opportunity to present its views and recommendations concerning H.R. 4437, the "Handicapped Independence Assistance Act of 1983." ASHA is the professional and scientific society representing over 39,000 speech-language pathologists and audiologists nationwide, many of whom are actively providing services to Medicare beneficiaries in acute care and rehabilitation hospitals, skilled nursing facilities, home health agencies, hospices, comprehensive outpatient rehabilitation facilities, and rehabilitation agencies.

The physically and mentally handicapped population comprises a substantial portion of the nation's population—around 35 million people. Among the most prevalent handicapping conditions are speech, language and hearing impairments. Because the ability to communicate effectively is so fundamental to other life activities such as learning, interpersonal relationships, vocational pursuits, etc., any loss or limitation of this ability can be detrimental to individual human development and performance.

AHSA's award of the Certificate of Clinical Competence (CCC) is the accepted indicator of professional competence in lieu of licensure. Licensure standards in 35 states establish educational and ethical standards which, like AHSA's, have a master's degree as the minimum educational accomplishment and require a nine-month Clinical Fellowship Year (CFY).

According to 1982 ASHA survey findings, 68% of ASHA members are providing direct clinical services. Over 20% of the members are primarily employed in health care settings, many of which are Medicare-recognized rehabilitation agencies. Speech-language pathology and/or audiology services are found in 44% of the nation's hospitals according to the American Hospital Association.

ASHA has projected that:

Between 1980 and 2050, the number of persons with speech and hearing impairments will increase at faster rates (54% and 102%, respectively) than total U.S. population (36%) as a direct result of the aging of the U.S. population. Because the prevalence of hearing impairments increases with age more rapidly than does the prevalence of speech impairments, the growth rate for persons with hearing impairments will exceed that for speech impairments for the next two decades.

As the numbers of persons with impairments increase, the two impaired populations will be growing older . . . the percentages of speech and hearing impaired persons age 65 and over were 20% and 43% respectively, in 1980, but will grow to 25% and 46% by 2000, and to 39% and 59% by 2050. (See Appendix II.)

A total of 1.9 million persons use hearing aids. This represents 13% of the hearing impaired. In the over 65 years of age group, 20% of all hearing impaired persons wore hearing aids. Among those with severe hearing impairments, 37% of this age group wore aids. (See Appendix IV.)

The natural sequela of severe cognitive and/or physical impairment, is an inability to produce intelligible speech and language for communicative purposes. At best, a small corpus of single words and/or short stereotyped utterances is used. If the disability affects the neuromuscular control of speech, even these productions will be distorted and often times, unintelligible. Although the underlying bases for the lack of speech and language are somewhat different for each group, congenital impairments such as mental retardation, cerebral palsy, muscular dystrophy, and autism as contracted with acquired disabilities such as stroke, head truma, amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease, and Huntington's chorea, may all result in an inability to communicate orally if the condition is severe enough. For the seriously impaired elderly individual, the communicative disorder may result in:

(1) Limited or nonexistent interactions with individuals or groups leading to social isolation and mental disturbances, (2) Increased possibility of institutionalization

caused by the above factor and exacerbating these conditions, (3) lack of means for indicating need for physical assistance in life threatening situations or the inability to understand urgent communications, (4) reduce independence, (5) reduced prospects for employment or voluntary activity.

Augmentative communication devices, when provided in a complete program of rehabilitation, provide a presently available avenue for most of these results to be avoided or ameliorated. Such services and devices are available under Medicaid in some states such as California, Oregon, Washington, Wisconsin, Illinois, Colorado, New Jersey, Massachusetts, and New York. They are provided in some very limited situations by the CHAMPUS program, in some state Crippled Children's programs, under the Education of All Handicapped Children Act, under Vocational Rehabilitation Programs, and under the Veterans Administration Services.

According to the Position Statement on Nonspeech Communication of the Association (see Appendix V), "Recent technological advances in the development of augmentative communication aids and systems have offered new options for the nonspeaking population. In addition, augmentative communication systems have been developed and/or applied differently to affect communication with this population. The combined use of these communication techniques and symbol systems has been found to be effective in augmentating residual speech skills, and providing communication access.

Given the state of the art regarding the development and use of communication techniques, there is no nonspeaking person too physically handicapped to be able to utilize some augmentative communication system."

It is therefore evident that the size of the Medicare population with serious communicative disorders is large and is growing rapidly. However, Medicare coverage of sevices needed by this population remains seriously deficient. ASHA is encouraged by the direction and leadership of the sponsors of H.R. 4437. However, we must point out that this bill only goes a partial way to resolve the serious obstacles to independent living of Medicare beneficiaries.

Comments on H.R 4437

ASHA is encouraged by the direction of H.R. 4437 to recognize the needs of the communicatively impaired Medicare population and to expand services available to these individuals. The legislation, in providing for funding for augmentative communication devices, may completely cover the needs of individuals who urgently need these devices. In addition, the proposed statutory language is broad enough to include many devices now available and likely to be available in the future.

The Association has three concerns to the proposed legislation in its current form. These relate to the financial caps included in the bill, the limited delivery system, and the ambiguity regarding the communication aid needed by the greatest number of communicatively handicapped persons - the hearing aid.

Regarding the limitation of $5,000 on the device, ASHA is concerned that the cost of some such devices may exceed this limitation. Appendix VI contains a chart provided by the Prentke Romich Company in February 1983. In indicates that of 44 devices listed, 14 may range in price from $2,000 to over $4,000. In addition to the cost of the instrument, the proposed legislation would include the cost of training in the use of such aids. Currently, some of this training cost might be covered under existing Medicare provisions such as the Outpatient Speech Pathology Benefit under Part B. However, the services of other professionals needed for appropriate fitting and training such as rehabilitation engineers, seating and fitting specialists and psychologists, are not included under current Part B provisions. If the cost of all the training regarding this devices were included under the $5,000 cap, then too little training in the devices might be provided, reducing the efficacy of the device to the Medicare beneficiary.

Secondly, the legislation, by assuming continuation of current Medicare practice requiring a physician prescription for such devices are provided to the communicatively impaired population. Speech-language pathologists and audiologists, by virture of their training, evaluate the need for the devices, select the most appropriate technique and symbol system and assure the skills essential to using the device in daily living.

The Committee on Ways and Means recognized the special role that speech-language pathology plays when it reported the Omibus Reconciliation Act of 1980. The Committee on Ways and Means commented on a change in the Medicare law, which provided that the plan of treatment for Medicare beneficiaries may be written by the speech-language pathologist or physican. The Committee stated:

"Present law requires that the patient be referred to the speech pathologist by a physician and that the physician establish and periodically review a plan of treat-

ment, which specifies the amount, duration, and scope of services to be furnished. Since speech pathology involves highly specialized knowledge and training, physicians generally do not specify a patient for such services. As a result, your Committee's bill allows either the physical or the speech pathologist to establish the plan of treatment so as to conform to Medicare law and related program policy to actual practice among the professions. The requirement for physician referral and periodic physician review of the plan of treatment would be retained." See House Report 96-588 (November 5, 1979).

In addition, in December 1983, the Office of Technology Assessment of the U.S. Congress issued its report, Assistive Devices for Severe Speech Impairments, as part of OTA's Assessment of Technology and Handicapped People.

"Probably more important is that assistive communication devices and systems are unfamiliar or unknown to most physicians. Rehabilitation medicine is, in general, a neglected topic in both undergraduate and graduate medical education where the thrust is more towards specialties and subspecialties dealing with the application of discreet technologies to particular organ systems than toward improving overall patient functioning. Very little course time is devoted to multiple physical disabilities and to multiple physical disabilities in conjunction with speech impairment, even for recently trained pediatricians and neurologists whose educational philosophies acknowledge the importance of the development of language and speech.

Moreover, physicians in the field of rehabilitation medicine, and thus likely to be aware of augmentative communication technology, are relatively few and not especially prestigious in the eyes of practitioners in more mainstream specialties such as surgery, internal medicine, family practice, pediatrics, etc. Rehabilitation specialists thus do not have a great deal of influence on their colleagues and on the fields.

These factors together have also conspired to give assistive communication technology little visibility in the medical literature. The publications with the widest physician readership such as the Journal of the American Medical Association, the New England Journal of Medicine and others, rarely, if ever, deal with the subject matter. Nor does the advertising. Thus, there is almost nothing in the professional environment of most physicians that would bring their attention to these issues. Since they have also received little attention from the lay media, there is little impetus for change in that direction either." (p. 41)

Therefore, it is the position of the Association that inclusion of augmentative communication devices under the Medicare system will be frustrated if the delivery system is predicated on educating physicians on the proper application of these devices. Such educational and efforts, in the experience of most of the members of the Association, is simply asking too much of the medical profession whose efforts to stay abreast of current medical information is being sorely tested. Rather, the Association believes that the delivery system for such devices should provide that they are available to the communicatively handicapped Medicare beneficiary on prescription of a physician or a qualified speech-language pathologist, or audiologist, where appropriate.

The third and most serious objection the Association has to this legislation is its ambiguity regarding hearing aids. While the legislation speaks to communication aids designed to substantially reduce or ameliorate handicaps caused by deafness or severe hearing impairment, it does not repeal the express prohibition in Medicare regarding hearing aids, which is contained in Section 1862(a)(7) of the Social Security Act.

The American Speech-Language-Hearing Association urges this Committee to clearly resolve this ambiguity in favor of the provision of hearing aids. For many years this Association has testified before this Committee and other bodies of the Congress in favor of this expansion of the Medicare system. It is clear that a great number of Medicare beneficiaries are hearing impaired. In fact, it is among the most common chronic condition of this population. The legislation purports to provide communication aids for the deaf and severely hearing impaired and yet is ambiguous on whether the most useful and widely needed device for this population will be provided or not. Such an omission can only result in years of disputes regarding the administration of this law and a great frustration on the part of the Medicare beneficiary. Our members are deeply concerned that should this bill become law, Medicare beneficiaries with hearing impairments will come seeking the provision of hearing aids under the Medicare statute and will be told that they are not available. Because passage of this legislation is very likely to raise the expectations of the hearing impaired Medicare beneficiaries and yet frustrate their hopes by not providing the most commonly needed device, the Association is oppposed to this legislation until it is clearly includes hearing aids.

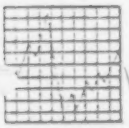
Medicare reforms for communicatively impaired

The American Speech-Language-Hearing Association believes that there are additional ways in which Medicare should be reformed to more adequately meet the needs of the communicatively impaired population. Devices alone are not adequate to meet the needs of this population. Without full access to services of qualified professionals, Medicare beneficiaries will continue to receive inadequate attention for their communicative disorders. In addition to providing reimbursement for communication aids, as proposed in H.R. 4437, Medicare should be amended to:

(a) include a provision of hearing aids when appropriate, (b) provide for coverage for independently practicing speech-language pathologists, (c) provide for reimbursement of rehabilitation agencies providing audiological services and those mandatory but nonreimbursed social work, vocational counseling, and psychological services, and (d) redefine the meaning of medical necessity as used by Medicare to include amelioration of communicative disorders.

In these ways Medicare can truly serve the needs of the communicatively impaired population. In spite of the financial difficulties facing the Medicare system, the Association believes that the growing population of communicatively impaired beneficiaries is presenting ever greater strains on our society. For this population, the services are available and the technological breakthroughs are on line. All that is lacking is the commitment by Congress to meet these needs and to assure the continued independence and productivity of this very large population. The American Speech-Language-Hearing Association looks forward to working with the Committee on Ways and Means to assure a fuller range of necessary services and devices will be available for communicatively impaired Medicare beneficiaries.

APPENDIX I
DATA PAGE



The Prevalence of Speech and Language Impairments

David J. Fein

There is only one source for speech impairment prevalence data that attempts to cover the general population of the United States: the National Health Interview Survey (HIS) of the National Center for Health Statistics (NCHS). How accurate are the HIS statistics?

Because they are based on reports from interviews with household heads and not on direct evaluation of family members, the HIS figures probably understate prevalence. In a national sample of public school students, for example, evaluation led to a prevalence rate as high as 3.8 times that found by the HIS in roughly the same age group (Hull, et al. 1976).

The restriction of HIS to cover only the noninstitutionalized population of the U.S. also reduces the prevalence rate for speech impairments, since prevalence is high in the institutionalized population. It has been estimated that 30% of the 2.0 million residents of long-term care institutions have a speech impairment (U.S. Bureau of Census, 1978 and 1982). Another feature of the HIS which causes the prevalence rate for speech impairments to be understated is its classification of "deaf persons who cannot speak" as hearing impaired only.

With these caveats, the most recent HIS estimate is that in 1980, 1.1% of the nation, or 2.3 million persons, had a speech impairment (NCHS, 1982). If direct evaluation leads to a prevalence rate as high as 3.8 times that found in interviews for the school-aged population, it may be reasonable to conclude that speech impairment is present in 4.2% of the population (3.8 x 1.1%), a figure not grossly discrepant from the often quoted 5% reported in 1952 by the ASHA Committee on the Midcentury White House Conference (Healey, et al. 1981).

The most recent year for which HIS prevalence rates are available for detailed age groups is 1977. Table 1 suggests a tendency for age-specific prevalence rates for speech impairments to increase at both extremes of age.

Table 1

Number and Rate per 100 Persons of Speech Impairments* by Age: 1977 U.S. Civilian, Noninstitutionalized Population

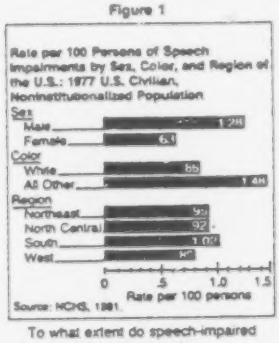
Age	Number	Rate Per 100 Persons
Under 5	140,018	.92
5-14	703,728	1.94
15-24	266,099	.67
25-34	221,213	.69
35-44	136,373	.59
45-54	149,171	.84
55-64	165,486	.82
65-74	127,825	.90
75+	84,623	1.06
All Ages	1,994,536	.54

*Excludes cleft palate cases and deaf persons who cannot speak.

The rate of speech impairments reported in health interviews is higher for males than for females, higher for non-Whites than for Whites, and about the same for each of the four major regions of the U.S., as displayed in Figure 1.

Figure 1

Rate per 100 Persons of Speech Impairments by Sex, Color, and Region of the U.S.: 1977 U.S. Civilian, Noninstitutionalized Population



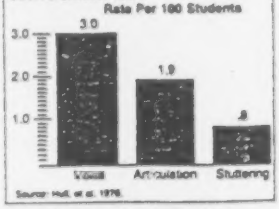
Source: NCHS, 1981.

To what extent do speech-impaired persons also have a hearing impairment? The 1971 HIS found 295,000 persons with both speech and hearing impairments: 15.2% of the speech-impaired population (NCHS, 1975).

Another frequently asked prevalence question concerns the causes, or etiology, of speech and language disorders. Unfortunately, diagnostic instruments have not been perfected to the point that specific primary causes can be reliably identified in large-scale empirical studies. The speech-impaired population is usually classified on the basis of exhibited behaviors, as exemplified in Figure 2.

Figure 2

Estimated Prevalence Rate per 100 Students of Voice Disorders, Articulation Disorders, and Stuttering in a National Sample of 38,802 Public School Students: 1968/69 School Year.



Source: Hull, et al. 1976.

For language impairments, too, "[m]ore precise definitions and diagnostic procedures are required" before we will have adequate prevalence data (Healey, et al. 1981). Although language impairments are probably included as "speech defects" in the HIS figures, they cannot be separately identified there. The 1982 Omnibus Survey of ASHA members indicated that 54% of speech-language pathologists' clients were primarily exhibiting language impairments.

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APPENDIX II

Projections of Speech and Hearing Impairments to 2050

CORRECTION*

David J. Fein

A wide range of governmental agencies and private organizations have come to rely on demographic projections. Federal planners working on the social security system look at how the population will age in the future; manufacturing industries examine potential future markets for their products; and service-oriented professions assess future service needs. To help members of the speech-language-hearing profession plan for the future, this month's "Data Page" presents projections of the numbers of speech and hearing-impaired persons in the United States.

The method used to make the projections discussed here is simple: for selected years between 1980 and 2050, 1977 age-specific speech and hearing prevalence rates were multiplied by projected U.S. population figures for the same age groups, and the resulting age-specific numbers of impairments were summed for each year.

Simple methods necessitate simplifying assumptions. In this case, the major assumptions are that: (1) future age-specific prevalence rates will be the same as the 1977 rates, and that (2) the Census Bureau's middle series projections of the United States population are reasonably accurate.*

Table 1 shows the numbers of persons with speech and hearing impairments and total U.S. population between the years 1960 and 2050.

Table 1.
Number of Persons with Speech and Hearing Impairments and U.S. Population: Selected Years, 1960 to 2050

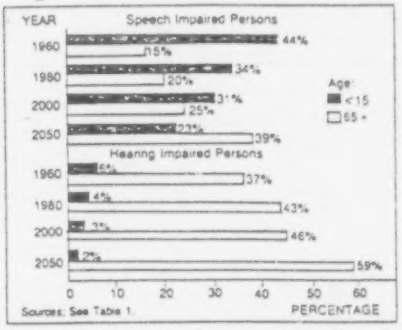
Year	Number of persons (in thousands)		U.S. population (in thousands)
	Speech impairments	Hearing impairments	
1960	2,115	12,974	180,671
1970	2,420	15,219	205,052
1980	2,598	18,075	227,658
1990	2,879	21,063	249,731
2000	3,141	24,027	267,990
2025	3,685	32,678	301,022
2050	3,994	36,511	308,856

Sources: NCHS, 1981; U.S. Bureau of the Census, 1974, 1978, 1982a, and 1982b.

Between 1980 and 2050, the numbers of persons with speech and hearing impairments will increase at faster rates (54% and 102%, respectively) than total U.S. population (36%) as a direct result of the aging of the U.S. population. Because the prevalence of hearing impairments increases with age more rapidly than does the prevalence of speech impairments, the growth rate for persons with hearing impairments will exceed that for speech impairments over the next two decades.

As the numbers of persons with impairments increase, the two impaired populations will be growing older, as Figure 1 shows. The percentages of speech and hearing-impaired persons aged 65 and over were 20% and 43% respectively in 1980, but will grow to 25% and 46% by 2000, and to 39% and 59% by 2050.

Figure 1.
Persons Aged Under 15 Years and 65 and Over as Percentages of the Total Numbers of Speech and Hearing Impaired: Selected Years, 1960-2050.



Sources: See Table 1.

*1977 rates were nearly identical to 1971 rates, suggesting that the first of these assumptions may be tenable, at least in the near future. Rates used in projections are from the 1977 National Health Interview Survey, adjusted to include the long-term care institutionalized population. The Census Bureau projections are discussed in U.S. Bureau of the Census, 1982b. A more detailed analysis than there is space for here would show how alternative assumptions would affect these projections.

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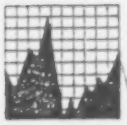
*The original publication (*Asha*, September 1983) reported incorrect figures in Table 1, columns 2 and 3. Ed.

DATA PAGE

APPENDIX III



The Prevalence of Hearing Impairment

Jerry Punch

Based on a variety of studies, the "best estimate" of the national prevalence of hearing impairment is that approximately 8% of the civilian, noninstitutionalized population of the U.S. experience some degree of difficulty in hearing or understanding speech. This estimate includes approximately 1% who are deaf, and is in general agreement with a recent total estimate of 17.4 million people who are hearing impaired (National Center for Health Statistics, 1982b).

Estimates of the prevalence of hearing disorders are based on data gathered by two primary methods: interviewing and audiometric examination. Among the recent studies using the interview technique is the National Health Interview Survey (HIS), conducted annually by the federal government. Detailed results on hearing were last published for the 1977 survey (NCHS, 1981, 1982a), and are summarized in Table 1. Information here is based on reports of hearing difficulties in one or both ears. Rates represent percentages relative to the U.S. population in each age group. Results show a progressive growth in the prevalence rate with increased age. For the total population over 65 years, the prevalence rate is 29.27% (not shown in Table 1).

The National Census of the Deaf Population, conducted in 1971 (Schein and Delk, 1974), concentrated on the deaf population—primarily on those who had lost their hearing prior to age 19 (the "prevocationally deaf"). Estimates in this study were based on interview data on a sample of the civilian, noninstitutionalized deaf population. Results yielded not only percentage estimates of the deaf, but also estimates of persons with significant bilateral impairments, and of all hearing-impaired persons. Some of the results are presented in Table 2, which includes updated numerical estimates based on April 1982 population estimates (U.S. Bureau of the Census, 1982).

Major audiometric surveys (i.e., screening and evaluation measurements) that have provided estimates of hearing impairment include the Health Examination Survey (HES) and the National Speech and Hearing Survey (Hull, Mielke, Willeford, and Timmons, 1976).

Data compiled from the 1960-62 HES (NCHS, 1965), for example, revealed hearing impairment in 8.4% of adults aged 18-79 years, as determined by average hearing levels in the better ear at 500, 1,000, and 2,000 Hz that exceeded 15 dB HL re the ASA, 1951 Standard.

The National Speech and Hearing Survey (Hull *et al.*, 1976), conducted by Colorado State University during the 1968-69 school year, measured pure tone air-conduction thresholds on a nationwide sample of 38,568 children in grades 1-12. Hearing impairment was defined as a pure tone average exceeding 25 dB HL re the ANSI, 1969 Standard. The survey revealed that 2.6% of these schoolage children exhibited hearing impairment. This total consisted of 1.87% who had unilateral impairments, and 0.73% who had bilateral impairments.

Table 1. Prevalence rates of hearing impairment, per 100 persons, in the civilian, noninstitutionalized population of the U.S. Rates are based on 1977 interview data.

Age Group in Years	Number	Prevalence Rate (%)
<5	96,034	0.63
5-14	592,595	1.63
15-24	922,012	2.32
25-34	1,380,760	4.29
35-44	1,344,130	5.82
45-54	2,269,974	9.79
55-64	3,095,322	15.35
65-74	3,430,852	24.10
75+	3,087,095	38.55
All	16,218,774	7.64

Source: NCHS, 1982b.

Table 2
Prevalence of hearing impairment, as reported in interviews, in the civilian, noninstitutionalized population of the U.S., by degree and age at onset (Schein and Delk, 1974).

Degree	Age at Onset	Percent of Total U.S. Population	Number*
All hearing impairment	All	6.803	15,250,883
Significant bilateral impairment	All	3.236	7,474,157
Deafness	All	0.873	2,016,359
	Prevocational†	0.203	468,867
	Prelingual‡	0.100	230,969

*Based on 1982 Census Bureau population estimates
†Prior to 19 years
‡Prior to 3 years

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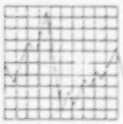
DATA PAGE



APPENDIX IV

Sociodemographic and Health Characteristics of the Hearing-Impaired Population

Jerry Punch

Some of the 1977 National Health Interview Survey (NHIS) results on hearing impairment were reported in the April 1983 "Data Page." The survey data base is analyzed on an ongoing basis by the National Center for Health Statistics (NCHS), and recent analyses of the data are highlighted in this report.

Estimates of hearing impairment from 1977 NHIS data include "deafness in one or both ears," "other trouble hearing in one or both ears," and "tinnitus or ringing in the ears." Earlier NCHS accounts of these data revealed that 16.2 million persons in the civilian non-institutionalized U.S. population 3 years of age and over experience some degree of hearing impairment. This overall figure included approximately 2 million people who reported tinnitus without accompanying hearing deficiency. A recent report by NCHS (1982) provides additional data on the sociodemographic and health characteristics of the 14.24 million persons reporting loss of hearing in one or both ears in 1977.

Of the total of 14.24 million hearing-impaired persons, 7.21 million (51%) had bilateral impairment, and 5.97 million (42%) had unilateral impairment, with the distinction between bilateral and unilateral hearing problems unclear in the remaining 7%.

Approximate degree of hearing impairment was established by questions asking whether the listener, without a hearing aid or speechreading, could hear and understand speech if a person: (1) whispers from across a quiet room, (2) talks in a normal voice from across a quiet room, (3) shouts from across a quiet room or, (4) speaks loudly into the better ear.

Sociodemographic Characteristics

Age, Sex and Race. Of normal-hearing individuals, 71% were between the ages of 3 and 44 years, 21% were aged 45-64, and 9% were 65 and over. Of the hearing impaired, 26%, 33% and 41% fell within these respective age categories. Males constituted a greater percentage of the hearing-impaired population (57%) than females (43%). Hearing impairment was more prevalent in white persons than in black persons in that whites constituted 88% of the normal-hearing population and 93% of those with hearing impairment. Data on other minorities were not reported.

Education and Incomes. For persons over 20 years of age, degree of hearing loss was inversely related to educational level. About 30% of the normal-hearing population over 20 had not graduated from high school, while 66% of persons with severe hearing impairment had not completed high school. Such a finding is perhaps to be expected, due to the well-known inherent limitations of severe hearing loss on educational attainment, as well as the observation that persons with lower educational levels seek and receive fewer medical services.

Of persons with normal hearing, only 21% lived with families having annual incomes under $7,000; 47% of the persons with severe hearing impairment lived in families at this income level.

Geographic Area. In comparison to persons with normal hearing, hearing-impaired persons were slightly underrepresented (by 2%) in the Northeast and overrepresented (by 2%) in the South. This regional distribution of impairments parallels the regional distribution of persons 65 and over.

Residence. A similar proportion (29%) of normal-hearing and hearing-impaired individuals (27%) lived in central cities of standard metropolitan statistical areas (SMSAs). The hearing impaired were slightly overrepresented in the less urbanized sections of the country and slightly underrepresented in suburban areas, relative to persons with normal hearing.

Health Characteristics

Self-Assessed Health Status. Respondents in the NHIS were asked to indicate whether they believed their health to be excellent, good, fair, or poor in comparison with other persons their age. The question was designed to yield an index of general health independently of any impairment the person might have. When compared to normal-hearing persons (11%), roughly three times as many persons with any degree of hearing impairment (31%) and about four times as many persons with severe hearing impairment (43%) judged their health to be fair or poor.

Specific Health Indexes. The hearing impaired had proportionally more annual "bed days," a measure of chronic and acute health conditions, more annual physician visits, and greater limitation of activity due to chronic conditions than did the normal hearing.

Hearing Aid Use. A total of 1.9 million persons used hearing aids. This represents 13% of the hearing impaired, contrasting somewhat with the 17% figure reported by Mahon (1982). Of individuals with severe hearing impairment, 34% wore hearing aids. In the age groups of 3-44, 45-64, and 65 years and over, 4%, 10%, and 20% of all hearing-impaired persons, respectively, wore hearing aids. Among those with severe impairments, 24%, 33%, and 37% in these respective groups wore aids. Among all hearing impaired, the use of hearing aids was distributed about equally for males and females.

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Committees

APPENDIX V

Position statement on nonspeech communication

The following position statement, drafted by the Ad Hoc Committee on Communication Processes and Nonspeaking Persons, was adopted as an official policy statement of the American Speech-Language-Hearing Association by its Legislative Council in November, 1980 (LC 15-80). 1980 committee members included: Billie Ackerman, ex officio; David R. Beukelman; Faith Carlson; Carol Cohen; Pam Elder; Suzanne Evans-Morris, public representative; Rich Foulds, public representative; Macalyne Fristoe; Linda F. Goodman; Debrah Harris; Arlene Kraat, public representative; Lyle Lloyd; Judy Montgomery; Howard Shane, chairman; Franklin G. Silverman; Barbara Sonies, Ronnie Wilber, public representative; Gregg Vanderheiden; James Viggiano, public representative; and David Yoder, Vice President for Clinical Affairs.

WHEREAS, the Executive Board of the American Speech-Language-Hearing Association (ASHA) established an Ad Hoc Committee on Communication Processes for Nonspeaking Persons, and

WHEREAS, one of the committee's charges was to develop a position statement for ASHA relative to its role in serving the communication needs of the more than 1½ million nonspeaking persons, and

WHEREAS, such a paper has been developed and published in the April, 1980 issue of *Asha* for peer review, and

WHEREAS, revisions of the position paper have been made to be in compliance with the ASHA Code of Ethics and the Council on Professional Standards in Speech-Language Pathology along with other membership concerns; therefore

LC 15-80. RESOLVED, That the position paper on Nonspeech Communication be adopted and disseminated in the same manner as have other position papers.

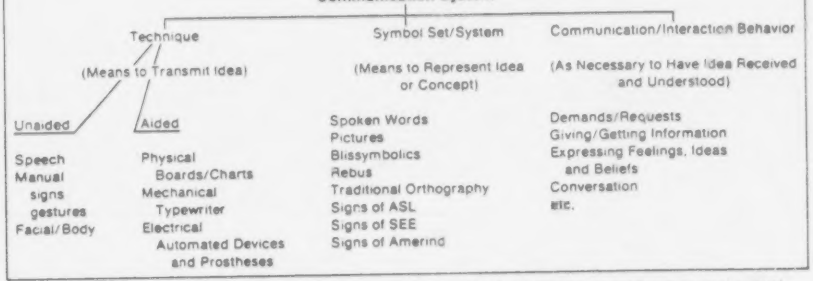
Recently, there has been a rapid and dramatic increase in the quality and quantity of services available to severely handicapped persons. Diversification of the provision of services to persons with multiple or severe handicaps has resulted in the expansion of professional competencies required of service providers. This situation has become particularly acute in those instances where professionals are assuming the responsibility of developing comprehensive service delivery programs for heretofore unserved or minimally served populations. One such group of individuals includes children, adolescents and adults who are nonspeaking and who usually exhibit to some degree neurological, emotional, physical or cognitive handicaps. It is encouraging that programs and services are now being made available to these persons, and that many advances have been made recently regarding the types of communication programs and systems which are available to them. Provision of effective and beneficial services and programs, however, depends upon the competencies of professional service providers. Although numerous professions will be included in the provision of communication services to the nonspeaking individual, speech-language pathologists should be primarily responsible for the development of treatment and intervention programs as such. Speech-language pathologists must have thorough working knowledge of and training in topic areas related to communication development for persons for whom speech may not be the primary mode of expression. There are a number of issues and concerns which relate to the development of such competencies in the speech-language pathologist. Issues of concern related to the design, implementation, and evaluation of communication programs for nonspeaking persons include: 1) terminology and delineation of client populations; 2) historical perspective related to service delivery in this area; 3) delineation of components involved in service delivery; 4) the role and professional responsibility of the speech-language pathologist in the provision of services; 5) impact of service needs on personnel preparation and the development of professional competencies; 6) professional ethics related to service delivery; and 7) current research and interprofessional activity needs.

Terminology

Numerous terms have been used to label the nonspeaking population, the methods used to improve their communication, and the intervention programs which have been used. The most frequent labels that are, and have been, used to describe the population include: severely speech impaired, speechless, nonoral, nonvocal, nonverbal, aphonic and nonspeaking. Operationally we are discussing a group of individuals for whom speech is temporarily or permanently inadequate to meet all of his or her communication needs, and whose inability to speak is not due primarily to a hearing impairment. In order to provide consistency with regard to terminology, the population under consideration will be referred to as nonspeaking persons. It is recognized that, although some of these individuals can produce a limited amount of speech, the speech exhibited is not adequate to meet all of their communication needs.

In order to provide effective communication systems for individuals whose speech is not fully functional a number of communication techniques have been developed which are in widespread use. Terms often used interchangeably to describe such communication techniques and programs include: nonoral, manual, nonvocal, gestural, nonspeech, nonverbal, alternative, assistive, augmentative, supplementary, aphonic, prosthetic and aided.

Figure 1.
Communication System



These communication techniques are seen as augmentative in that they are designed and utilized in such a manner as to supplement whatever vocal skills the individual may possess. The term augmentative will, therefore, be used to refer to this general classification of procedures which include both aided and unaided communicative techniques.

The term *augmentative communication system* will be used to refer to the total functional communication system of an individual which includes: 1) a communicative technique; 2) a symbol set or system; and 3) Communication/Interaction Behavior (See Figure 1).

The term *unaided* will be used to refer to all techniques which do not require any physical aids. Manual, gestural, manual/visual, sign or facial communication as well as oral speaking are considered *unaided communication* techniques (see Figure 1).

The term *aided* will be used to refer to all techniques where some type of physical object or device is used. Techniques which use communication boards, charts, and mechanical or electrical aids are considered *aided* communication techniques.

Symbols and symbol systems refer to the means to represent ideas and concepts. Examples of symbol sets/systems include spoken words, pictures, Blissymbolics, Rebus, traditional orthography, signs of American Sign Language, signs of Signing Exact English, and signs of Amerind (see Figure 1).

It should be recognized and cautioned that these "definitions" are generic and that speech-language pathologists should describe and provide specific detail regarding the etiology of the nonspeaking condition when referring to clients, and to the specific type of communication technique and intervention program used.

Historial perspective on service delivery

Historically, nonspeaking persons were placed in a speech treatment program or not given treatment, because oral speech did not appear to be feasible. Some pioneering efforts were made by a small number of speech-language pathologists and others in the development and use of communication boards for the severely physically handicapped or the use of manual signs with hearing, mentally retarded persons.

Recent technological advances in the development of augmentative communication aids and systems have offered new options for the nonspeaking population. In addition, augmentative communication systems have been developed, and/or applied differently, to effect communication with this population. The combined use of these communication techniques and symbol systems have been found to be effective in augmenting residual speech skills, and providing communication access.

Given the state of the art regarding the development and use of communication techniques, there is no nonspeaking person too physically handicapped to be able to utilize some augmentative communication system. Therefore, the speech and language professional is now faced with increasingly diverse program and treatment options for nonspeaking persons and she/he must develop the competency necessary to serve these clinical needs.

A large, previously untreated population exists. Recent prevalence figures indicate that there are over one million children and adults who are nonspeaking as a result of neurological, physical, emotional or cognitive disability. The development of effective communication systems is a current unmet need of these persons, and a need which will become the primary responsibility of speech and language professionals. For example, recent legislation (PL 94-142) mandates the development and implementation of effective educational programs for all handicapped persons under 22 years of age. As a result, many nonspeaking persons are currently being enrolled in educational programs. Their success depends upon the acquisition and demonstration of competent communication skills. The above factor alone will dramatically increase the number and diversity of nonspeaking persons on the speech and language professional's caseload within an educational setting. Another factor which will affect provision of service involves recent advances in the development and use of communication techniques and symbol systems.

Recent rapid advances in the development of augmentative communication systems has been

fortunate for nonspeaking persons. At present, there is a critical need to supplement the speech and language professional's current knowledge of basic speech, language, and communication processes with training specifically dealing with the development and implementation of augmentative communication systems.

Components involved in service delivery

1) Assessment to Determine the Need and Appropriateness of an Augmentative Communication System or Systems:

In order to determine the need for the development and use of an augmentative system, and the intervention entry point, the nonspeaking persons should be assessed with regard to physical, sensory, emotional, and cognitive ability; speech and language skills; correct seating and positioning; general communication skills; communication needs (conversational and written) for social, emotional, educational and/or vocational purposes; family needs; and nature and quality of supportive services.

2) Selection and Development of An Effective Augmentative Communication/Interaction System or Systems:

Once the need for intervention has been decided, specific exploration related to selection and development of augmentative systems, which can provide the individual with the most effective and functional communication, needs to be explored. This involves consideration of unaided and aided communication techniques. In addition to determining the physical expressive means, an appropriate symbol system through which communicative messages can be formulated and expressed needs to be developed. This involves consideration of symbol systems.

3) Developing Interactive Skills:

Once an augmentative communication approach has been selected, the nonspeaking person will need to be provided with training in skills which will enable him/her to utilize the augmentative technique and symbol system in such a manner as to be able to achieve communicative competence as defined by the message-receiving community. This training includes: use of appropriate technique and selected symbols, strategies for developing effective communication interaction, as well as the training of persons who interact or potentially will interact with augmentative communication system users.

4) Follow Up and Ongoing Evaluation:

Appropriate implementation should include continual evaluation of the communication/interaction effected by the system, appropriate alteration of the system and communication strategies if indicated, and preparatory training for future use of different or more complex systems.

Role of the speech-language pathologist

Depending upon the particular needs of the client, the interdisciplinary evaluation team may include any or all of the following: speech-language pathologist, physical therapist, occupational therapist, educator, medical specialists, audiologist, psychologist, seating and fitting specialist, engineer, social worker, vocational counselor, vendors, third party agent, extended family and friends, primary caregivers, and the client.

The central role in initiating and coordinating the services of this team should be taken by the person most likely to initiate the recommendation for an augmentative communication system, based on his/her evaluation of the client's oral motor performance, language competence, and communication needs. Further, the person needs to possess the knowledge of language development and communication interaction which will be essential to the client's success in augmentative communication. In most cases the speech-language pathologist would be the person who best meets these requirements.

Therefore, the professional role of the speech-language pathologist in providing services to nonspeaking persons includes:

1) Assessing, describing, documenting, and continually evaluating the communication/interaction behaviors and needs of these persons;
2) Evaluating and assisting in the selection of the various communication techniques in order to develop an effective repertoire of communicative modes;
3) Developing speech and vocal communication to the fullest extent possible;
4) Evaluating and selecting the symbol systems for use with above selected techniques;
5) Developing (and evaluating the effectiveness of) intervention procedures to teach the skills necessary to utilize augmentative systems in an optimal manner;
6) Integrating assessment and program procedures with family members and other professional team members;
7) Training of persons who interact with the nonspeaking individual; and,
8) Coordination of augmentative communication services.

In addition to the above, another primary role of the speech-language pathologist is that of client advocacy. Although there is continual increase in the use of nonvocal communication modes, there remains, for the most part, a knowledge/experience gap in terms of the general public's acceptance and understanding of these modes. Successful communication development programs necessitate that speech-language pathologists help clients to develop effective skills with which to interact with both speaking and other nonspeaking persons in their community. In order to achieve this, and in order to help clients secure financial support for needed communication prostheses, clinicians must be able to serve as client advocates—educating their co-workers and communities about nonspeech communication in general and their client's needs in particular.

Personnel preparation

Current training should provide speech-language pathologists with competency in the areas of basic

speech, language, and hearing processes. Training in competency areas specifically related to the development and use of augmentative communication systems has not been incorporated into most programs. This latter training should include the development of competencies specifically related to:

1) Assessment procedures for determining augmentative communication system candidacy, and selection of system components;
2) Assessment of prelinguistic communicative interaction strategies in nonspeaking persons;
3) Knowledge of currently available aided and unaided techniques;
4) Knowledge of available symbol options;
5) Knowledge of the nature of augmentative communication in interaction with speaking and nonspeaking persons;
6) Development and evaluation of communication intervention programs specifically designed to teach nonspeaking persons those skills needed in order to achieve communication competence via augmentative communication techniques;
7) Knowledge of the effect of appropriate seating and positioning on the user's control of the speech mechanism and on a nonspeaker's communication technique; and,
8) Advocacy and funding procedures.

Professional ethics related to service delivery for nonspeaking persons

The revised Code of Ethics of the American Speech-Language-Hearing Association effective January 1, 1979, stresses the professional responsibility of speech-language pathologists and audiologists in providing services. For those individuals who serve nonspeaking persons and recommend augmentative communication systems, several fundamental rules of ethical conduct are particularly relevant:

Training:

> *"Individuals shall maintain high standards of professional competence* . . . Individuals must neither provide services for which they have not been properly prepared, nor permit services to be provided by any of their staff who are not properly prepared" (Principle of Ethics II, Ethical Proscription 1).

Few education and training programs include instruction or clinical experience in augmentative communication. Therefore, speech-language pathologists and audiologists who lack formal training in nonspeech communication must assume responsibility for continuing education by reading, attending meetings and workshops, seeking consultation, and other means of increasing their knowledge and competence about this aspect of habilitation.

Services:

> *"Individuals shall hold paramount the welfare of persons served professionally.* Individuals shall use every resource available, including referral to other specialists as needed, to provide the best service possible" (Principle of Ethics I, A).

If a speech-language pathologist or audiologist is unable to adequately assess and instruct clients in the use of augmentative communication systems, the client should be referred to a specialist who can provide appropriate services. Furthermore, it appears to us that the speech-language pathologist has the obligation, despite his/her own bias with regard to speech and an augmentative communication system, to inform the individual and his/her family about the existence of those systems and the available options for communication.

> *"Individuals shall honor their responsibilities to the public, their profession, and their relationship with colleagues and members of allied professions* . . . Individuals should strive to increase knowledge within the profession and share research with colleagues . . . establish harmonious relations with colleagues and members of other professions . . . inform members of related professions . . . as well as seek information from them" (Principle of Ethics V, Professional Propriety 3, 4).

Speech-language pathologists and audiologists who are knowledgeable about augmentative communication have a professional responsibility to share information which will benefit communicatively handicapped individuals. Providing nonspeaking persons with augmentative communication devices necessitates interdisciplinary cooperation. Therefore, it is imperative that parents, physical therapists, occupational therapists, psychologists, teachers, physicians, and other specialists involved in providing service to a nonspeaking person be provided and share information about augmentative communication systems.

Dispensing of products

> *"Individuals shall maintain objectivity in all matters concerning the welfare of persons served professionally.* Individuals who dispense products to persons served professionally shall observe the following standards:
> (1) Products associated with professional practice must be dispensed to the person served as part of a program of comprehensive habilitative care.
> (2) Fees established for professional services must be independent of whether a product is dispensed.
> (3) Persons served must be provided freedom of choice for the source of services and products.
> (4) Price information about professional services rendered and products dispensed must be disclosed by providing to, or posting for, persons served a complete schedule of fees and charges in advance of rendering services, which schedule differentiates between fees for professional services and charges for products dispensed.
> (5) Products dispensed to the person served must be evaluated to determine effectiveness" (Principle of Ethics IV, A).

In order to dispense augmentative communication devices, speech-language pathologists and audiologists must observe the ethical principles stated above. In addition, they should have an adequate knowledge of various types of devices in order to make a judicious

evaluation and recommendation. Ideally, several communication devices should be available to permit a nonspeaking person to use a device prior to the selection and purchase of one.

Current research and interprofessional activity needs

Attention to the needs of nonspeaking persons has grown so rapidly that the "consumer market" and client population is currently overwhelmed with the variety of aided and unaided techniques and program options available, and with the lack of substantive information regarding the use, applicability, and effectiveness of each. As a result, service delivery programs are being implemented in an unorganized fashion and many client's needs are not being met or are being met in an inappropriate manner.

Therefore, critical research needs and questions are:

1) What are the most effective strategies for:
   a. symbol acquisition;
   b. learning to use aided and unaided techniques;
   c. facilitating interaction?
2) Considering the physical, cognitive, linguistic and communication parameters of the nonspeaking person, which available augmentative systems best meet his/her needs?
3) If clinical observations regarding increase in vocalizations following exposure to augmentative communication systems are correct, why is this so?
4) What is the role of iconicity in the learning of a symbol system?
5) How can spontaneous communication be encouraged?
6) Which factors, singly or in combination, make a person high risk for not becoming an oral communicator?
7) How can interaction best be fostered between speaking and nonspeaking persons?
8) What are effective means of increasing rate of communication by augmentative communication systems users?
9) Does the language development of users of augmentative systems parallel that of normal language development?

In addition, the Committee sees the need for:

1) Greater investigation and use of electronic and computer-assisted systems; and
2) The development of tests and procedures for assessing the communication abilities of the nonspeaking population.

As regards future interprofessional activities, there is a need to develop some vehicle/organization which can:

- —provide a "common ground" for written and verbal communication between professionals from the diverse disciplines which serve nonspeaking persons;
- —assume an active role in advocating and providing for the nonspeaking client's communication needs; and
- —disseminate information in the area to professionals, parents, and nonspeaking persons.

Mr. MATSUI. Thank you.
Carol Cohen.

STATEMENT OF CAROL COHEN, SPEECH PATHOLOGIST/COMMUNICATIONS SPECIALIST AND DIRECTOR, SCHNEIER COMMUNICATION UNIT, CEREBRAL PALSY CENTER, SYRACUSE, N.Y.

Ms. COHEN. Thank you, Mr. Chairman.

The First Amendment to the Constitution of this great Nation guarantees its citizens freedom of speech. I believe it is time we recognize that an approximate 1½ million children and adults are unable to enjoy this inalienable right. Today I speak for the nonspeaking consumers of our country who because of severe speech impairments are unable to communicate vocally. I am also representing the many professionals, manufacturers, families, teachers, and friends of the communicatively handicapped who share my comments and concerns and respectfully ask you to support this important legislation.

Communication, the transmission of information, ideas, and thoughts from one individual to another, is a basic human need. Without the ability to communicate, we are isolated. We lack self respect because of a reduced capacity to interact in our community. We are cognizant of message recipients' impatience and discomfort when we are unable to intelligibly and swiftly exchange messages. The frustration and anxiety we feel is disabling and demeaning.

Today, however, there is a brighter future for severely communicatively impaired individuals. As a result of the federally sponsored and subsidized space exploration program, a vast plethora of technological aids and devices are commercially available for able-bodied as well as for disabled persons. These systems facilitate autonomy and independence while providing the communicatively disabled with a conduit for achieving their full potential in educational and vocational arenas.

Sensory aids which augment or supplement expressive communication can generate synthesized speech, control electric appliances in the environment, dial a phone and signal for medical assistance, produce hard copy/printed materials, and interface with other proshtetic devices.

The national office of the United Cerebral Palsy Association created their own bill of rights pertaining to the disabled which, to paraphrase, ". . . the right to necessary assistance given in a way that promotes independence . . . a choice of life style, . . . self esteem." This cannot be possible without a means of delivering effective, intelligible, reliable, interactive communication.

Communication devices, therefore, must be considered an undeniable medical necessity and as such will foster increased independence and rehabilitation. Further the implementation of sensory devices will result in a concomitant reduction of dependence and preclude the perpetuation of a segregated handicapped society.

I suggest that expressive communication impairments which may be ameliorated through assistance and training with the most appropriate communication instrument will become in our lifetime a technological and sociological artifact. It will be no more unusual to view a nonspeaking person with a modified personal computer

system as normal as it is to perceive of a wearer of eyeglasses as normal.

The lawmaking body of our Nation must create a viable source of revenue which treats sensory and communication aids as medical and health services, reimbursable under medicare and medicaid.

I would like to share a personal account with you in my last few moments. Let me state that I am a clinical supervisor in central New York, and I am responsible for communication evaluations, device prescriptions, training and educational services for over 100 severely communicatively impaired children and adults each year. Many of the individuals referred to our program have some form of Federal subsidy. They may have medicaid, for example.

The case I would like to share with you is typical of the capricious nature of Federal subsidy review for communication aids and related devices. There seems to be a pervasive ambiguity and lack of uniformity in policy, practice and procedure in the medicare-medicaid review process.

Kevin is a 24-year-old gentleman who resides in an extremely remote rural area in the northern Adirondack Mountain region. He is cerebral palsied, spastic quadraparalysis, and is nonspeaking. He is unable to intelligibly communicate his needs to anyone except his mother.

For the past 4½ years Kevin has been attending Clinton Community College. The only way he has been able to accomplish this is because his mother accompanies him every day regardless of the weather. He graduated from this particular community college with a B-plus average.

I don't know if the people in this room know what effort and courage it took for this young man to have achieved this. He completed his homework and term papers by typing letter by letter with a mouth stick and did this each night for approximately 4 years; many, many hours each night. One of his teachers read of our program in a local newspaper, and she referred Kevin to us.

Many, many months later Kevin and his mother and some friends made the trip to Syracuse from the Adirondacks. There was no question as far as we were concerned that this young man was an exemplary candidate for an advanced technological system. We applied to medicaid. I would like to tell you that 2 years later and five submissions later, we finally received the funding.

But the purpose of my sharing this with you is that in the meantime, this young man languished in an area where he was totally isolated from the rest of the world. With the computer that we were recommending for him, he could have spoken over the telephone, generated his paperwork, and made a real contribution. He could have perhaps developed a small business out of his home.

But he was unable to do this because of the inconsistencies in our system. We did eventually receive the money, and I am convinced that this was the result of an erosion of the reviewers' stamina to continue denying.

We must not allow this to continue. There are hundreds and thousands of people like this young man. Fortunately, there is a happy ending to this story. But many of these cases do not have happy endings. We must have some kind of regulation based upon acceptable practices and reasonable justifications.

I agree that H.R. 4437 as it stands is in some need of revision and modification. But the underlying premise remains constant. We need a reliable source of revenue to tap for appropriate device utilization and implementation. Allow me to conclude my testimony by reading one statement.

The owner of a small computer business who lived in Kevin's area lent him a computer for a number of months. He wrote to me. The following is what he said after working with Kevin on four consecutive Sunday afternoons.

I know that he is an extremely acute listener and does have a retentive creative mind.

I feel that he could learn to use such a device and that it would assist him in interfacing with the otherwise cold world out there. He has little else to do in life except become a computer expert with his own computer and should he study his machine and become this expert, he could earn a living which might permanently remove his status as a financial burden on society.

Consider the psychological ramifications for Kevin if this should be accomplished. I have little to gain in writing this letter except to prove a point.

This gentleman did not know I was going to read his statement, but I thought you might find it interesting. He had nothing but his own personal satisfaction to gain.

I thank you very much for your attention.

[The prepared statement follows:]

STATEMENT OF CAROL COHEN, DIRECTOR, SCHNEIER COMMUNICATION UNIT, CEREBRAL PALSY CENTER, SYRACUSE, N.Y.

The first amendment to the constitution of this great Nation guarantees its citizens freedom of speech. I believe it is time we recognize that an approximate one and a half million children and adults are unable to enjoy this inalienable right. Today, I speak for the "non-speaking" consummers of our country who, because of servere speech impairments, are unable to communicate vocally. I am also representing the many professionals, manufacturers, families, teachers and friends of the communicatively handicapped who share my comments and concerns and respectfully ask you to support this important legislation.

Communication, the transmission of information, ideas, and thoughts from one individual to another is a basic human need. Without the ability to communicate, we are isolated. We lack self respect because of a reduced capacity to interact in our community. We are congnizant of message recipients' impatience and discomfort when we are unable to intelligibly and swiftly exchange messages. The frustration and anixiety we feel is disabling and demeaning.

Today, however, there is a brighter future for severely communicatively impaired individuals. As a result of the federally sponsored and subsidized space exploration program, a vast plethora of technological aids and devices are commercially available for disabled and able-bodied persons. These systems facilitate autonomy and independence while providing the communicatively disabled with a conduit for achieving their full potential in educational and vocational arenas.

Sensory aids which augment or supplement expressive communication can generate synthesized speech, control electric appliances in the environment, dial a phone and signal for medical assistance, produce hard copy/printed materials and interface with other prosthetic devices.

The national office of the United Cerebral Palsy Association created their own bill of rights pertaining to the disabled. To paraphrase, "The right to necessary assistance given in a way that promotes independence, a choice of life style, self esteem". This will not be possible without a means of delivering effective, intelligible, reliable, interactive communicative responses.

Communication devices therefore must be considered an undeniable medical necessity and as such will foster increased independence and rehabilitation. Further, the implementation of sensory devices will result in a concommitant reduction in dependence and preclude the perpetuation of a segregated handicapped society.

I suggest that expressive communication impairments which may be ameliorated through assistance and training with the most appropriate communication instrument will become in our lifetime a technological and sociological artifact. It will be

no more unusual to view a non-speaking person with a modified personal computer system as 'normal' as it is to perceive a wearer of eye glasses as normal!

The technology the professional expertise, the motivation, and the dreams of the disabled are tangible products of our heightened sensitivity to the debilitating nature of communication handicaps. The law making body of our Nation must create a viable source of revenue which treats sensory and communication aids as medical and health services, reimbursable under medicare and medicaid. Most handicapped individuals do not possess the financial means to purchase communication equipment.

To reiterate Representative Brown's astute comments, "Wider acquisition of such aids, equipment, and devices by persons with disabilities would benefit the national economy, disabled persons, and their families through increased employment, independence, and improved education for such persons, and is therefore in the national interest".

Mr. MATSUI. Thank you.

Mr. Moore, do you have any questions?

Mr. MOORE. No questions, Mr. Chairman.

Mr. MATSUI. I would like to thank both of you, Ms. Cohen and Mr. Downey, for coming here today and giving us your very valuable testimony.

Mr. DOWNEY. Thank you very much.

Ms. COHEN. Thank you.

Mr. MATSUI. I would like to call the last panel at this time, Roderick McDonald, president of the American Association for the Deaf-Blind; Delores Follette from Carmichael, Calif.; Mr. Stone is not able to be here today, so we will hear from Mr. McDonald and Ms. Follette.

I might add while Ms. Follette is coming up, she happens to reside in Carmichael, Calif., which is a suburb of Sacramento, Calif., the area in which I happen to live and represent. That is not why she is here, however. She is here on her own merit.

We will call at this time on Mr. McDonald to testify. Again, as I mentioned to the other members of the panels before you, your written testimony without exception, will be submitted for the record. You may, however, read your written testimony or you may summarize it. Mr. McDonald.

STATEMENT OF RODERICK J. McDONALD, PRESIDENT, AMERICAN ASSOCIATION FOR THE DEAF-BLIND

Mr. MCDONALD. Thank you, Mr. Chairman.

My name is Roderick McDonald. I am president of the American Association of the Deaf Blind, a national consumer organization of deaf-blind people and others with an interest in our welfare. I am here today to express our very strong support for the legislation you are considering which we feel would be especially beneficial to deaf-blind people.

The most critical problem faced by all deaf-blind people is isolation. Isolation from information, isolation from ideas, isolation from other people. Because of this problem, many deaf-blind people live lonely isolated lives despite the fact that many have abilities which they never have the opportunity to use.

In recent years a number of special aids and devices have been developed, often as the result of research funded by the Federal Government. These devices in many instances enable deaf-blind people to make effective use of their abilities, allow them to utilize

existing services which hitherto were inaccessible because the necessary communication links could not be bridged.

The problem, however, is that these devices often are out of the financial reach of the vast majority of the people who could most benefit from them. To cite just one example, the telebraille, a telecommunications device designed specifically to meet the communication needs of deaf-blind people who read braille, has been enthusiastically received by deaf-blind people, but carries a daunting price tag of $5500, a sum greater than the entire yearly income of many deaf-blind people.

With this device a deaf-blind person can communicate both receptively and expressively with anyone who can type. It can be used in face-to-face communication situations or over the telephone. It can even access computerized information systems. The tragedy is that while the Federal Government has spent large sums to support the development of this device, nothing has yet been done to make it available to deaf-blind people.

We feel the legislation you are considering would go a long way toward correcting this problem. Deaf-blind people would be encouraged to evaluate existing equipment and choose the devices most beneficial to them, while industry would be encouraged to develop new products irrespective of the financial situation of the people to whom the products are intended. State agencies would be able to provide better services because a wider range of vocational and educational opportunities would be open, and not least importantly, deaf-blind people would be spared the indignity of having to ask local service clubs for charity in order to acquire the devices vital to their making the best use of their abilities.

We would like to emphasize here that the provision of assistive devices of this nature cannot be considered ideally situated to the open marketplace. Typically the greatest need, and therefore the primary demand, will come from a comparatively small group of people who are least able to provide. And society has an obligation to correct this situation.

Mr. Chairman, we feel there is a particular element of urgency in this situation. Deaf-blindness is one of the most severely limiting of all disabilities. Yet in many cases, imaginative solutions to complex problems have been and can be found. But we must still put these solutions to use. With your help, this will be done.

Thank you.

Mr. MATSUI. Thank you very much, Mr. McDonald.

Ms. Follette.

STATEMENT OF DELORES FOLLETTE, CARMICHAEL, CALIF.

Ms. FOLLETTE. Mr. Chairman, my name is Delores Follette. I have been totally blind since I was 2 years old. And I have had severe hearing problems since the age of 10. I have been very fortunate in that I was able to hear with the help of hearing aids until 1970, when I became completely deaf. I am married and the mother of four children. I am a student at California State University where I am studying social work. I hope to find employment as a counselor with deaf-blind, or deaf-blind people after I graduate.

When people ask me what I miss most, my answer is that I miss being able to pick up the telephone and frequently make a call without assistance of another person. Although I have a wonderful home and loving family, I must admit a feeling of loneliness when it is not possible for me to reach out to others, when I must wait for them to come to me.

I would like to tell you something about a wonderful device which we have recently developed for use for deaf-blind people. This device is called the telebraille, and I have had the opportunity of using it for a total of four months. I feel the telebraille is one of the most fantastic things that has ever happened in my life.

The first day I had the machine for field testing, I stayed on the telephone nearly 24 hours. My family and friends, especially my husband, felt it was wonderful to be able to communicate directly with me without need of an interpreter. The feeling of independence this gave me was like a seventh heaven. I feel that to complete my education and searching for a job, this device greatly decreases my dependence on others and makes me believe that many new doors are open to me.

Mr. Chairman, imagine the freedom. The first question I am asked in a job interview is always, "How will I communicate with others?" With this machine that will not be a problem.

The second question I am always asked is, "How will I be able to cope with an emergency?" With this machine I feel I will be able to handle almost any situation that is likely to arise. I could call for help if I needed it. There might be a fire or an urgent need to call a doctor. This device would make it possible to do that.

I have also found this wonderful machine to be very useful in communicating face to face with others. I have used it in meeting with my doctor and with my attorney, and I have found it is especially helpful when I am traveling. It eliminates the need of an interpreter. And in an interview with your doctor or attorney, or even with other persons, it gives you a feeling of complete privacy which you do not always feel with a third person present. This is true even though that third person might be your most trusted friend.

Most deaf-blind people do not have jobs. Their sole income is SSI and SSDI. How can we possibly afford a device that costs $5500? I am here today to ask your support so that the door of independence might be opened for a fuller, richer life experience for the deaf-blind. The legislation you are considering is a means of providing independence, of reducing isolation which is such a major factor in the lives of deaf-blind people. We very much need your help.

Thank you, sir.

Mr. MATSUI. Thank you very much, Ms. Follette.

Mr. Moore, any questions?

Mr. MOORE. No questions, Mr. Chairman.

Thank you.

Mr. MATSUI. Thank you both very much.

I want to tell you that I enjoyed talking with you, Ms. Follette, before the hearing today. As I indicated to you when you advised me that you were on the phone 24 hours after getting this device, that any time you want to volunteer a few hours in my office to

answer my phone calls, please give me a call, and we will set that up.

I want to thank you again, both, very much for testifying.

Ms. FOLLETTE. Sure will, thank you. Love it.

Mr. MATSUI. Thank you.

I would like to call at this time Denyse DuBrucq with the Ear Three Systems.

STATEMENT OF DENYSE C. DuBRUCQ, ED.D., CHIEF EXECUTIVE OFFICER, EAR THREE SYSTEMS, PROVIDENCE, R.I.

Ms. DUBRUCQ. Good afternoon, Mr. Chairman.

Mr. MATSUI. Your written testimony, without objection will be submitted for the record. You may read it, or you may summarize it.

Ms. DUBRUCQ. All right, I will stick to some degree to it, and put a few elaborations in and cut some, if you don't mind.

I greatly appreciate this opportunity, Congressman Brown and Acting Chairman Matsui. Let me first define my activities in hearing impairment. I have consulted for Gallaudet for a length of time since 1976 and became involved in cued speech, wanting to animate it in some manner for computer output. While I was working on the project the means of coding speech in real time in a tactical code that would be similar to ear hearing became evident. The device developed is a wrist-worn device which takes up about 3½ inches on the wrist. It is driven by a real time speech and sound analyzer, which is presently 85 percent completed in its software development.

The point of my testimony is mostly that we have been starved out from Federal assistance in developing the device because of people active in the field presently.

In the United States, I find the present method of funding the handicapped area preserves the status quo, preserves the handicaps and the jobs related. I thought that we had an out in the small business innovative research program which could cause a change. However, they were captured into by university-related activities.

In over $1 million in applied requests for Federal support, only $30,000 as a NSF-SBIR grant was awarded, and this was the first grant that we had applied for, before anyone had figured out just what we had when we were developing the device. On a deaf-blind proposal to NIH, Lou Braida, who heads the MIT team, or the whole committee, came out in the review exceedingly critical of my capabilities.

My strong points in inventing over a period of 15 years is that I do understand human cognition and perception. In that review they knocked every bit of that. I don't see how anyone could realize what it is a person is developing and not see those kinds of qualities.

Anyway, in looking at how things are going, if something were to happen today to remove the difficulty of hearing impairment and have people hearing with a device which would totally articulate the speech message in real time, along with giving pitch, then the funding for various university programs which essentially are still looking and seeking for devices and ways to help these people,

would possibly be reduced. And with the moneys that are being spent presently in this research area by NIH and NSF, Office of Education, and Handicapped Research, how many people are really being helped?

In papers I have read over 4 years I find there is a handful of research subjects so aided, while 11 million severely bilaterally hearing impaired and deaf persons wait, and 66,000 students with severe and total hearing loss remain in special education. I very strongly support your bills, both House bill 4437 and the accompanying Senate bill, S. 1115. Both of these will pay for the winners, the performers in developing aids for the handicapped, not the researchers who want to perpetuate and try different things which don't seem to have an active end in solving the problem.

To bring aid to the situation I am offering you the opportunity to make an example with Ear Three Systems. We are about 6 months out from having a complete, marketable product. We have the talent for succeeding in preparing for market, mass producing the TactilEar. It retails for $750 for the device and $200 for the 20 lesson instructional series.

I can solve the problem of hearing loss better than universities because, besides knowing what I am doing and can do, I have the means ready to produce, to meet the needs of the deaf quickly. Working with Ear Three Systems are Digital Equipment Corp., RCA Corp., Phonetigraphics, Inc., in Scottsdale, Ariz., and Eng Manufacturing, an engineering firm which makes parts for the auto industry which will produce the analyzer. We are ready to put forth a device which will allow deaf people to hear. I request you take this opportunity to portion out one area of study, measuring private industry capability using Ear Three Systems to solve a major problem today—deafness. Private industry acts faster than universities and therefore can serve more people faster.

Two examples of Government sponsorship are evident: first, the ConvAid device we are using for a model speech for listening development is produced by Government sponsorship in Britain. We are very pleased to be a part of that activity. Second, in the auto industry, the Chrysler Corp. has been supported in its dire straits in the last 3 years.

Ear Three Systems has to date received $30,000 in Federal moneys; has borrowed in venture capital, including interest, $115,000; presently owes $70,000 in bills; and is seeking $3.5 million to launch the TactilEar on the commercial market.

By the end of 1984, with funds, we can have completed our 3 months of marketing in Rhode Island, our model marketing State, and can be starting the national distribution opening 10 Listen-Ears, which are the distribution points, per week.

This endeavor, this experiment in industrial support in a humanitarian area, has the same job-rich opportunity as was defined with Chrysler, and instead of feeding a competitive market with one more product persisting, we are entering the market with a revolutionary device that will enable deaf persons to hear.

My choices of initial employees in Rhode Island with their employment security job training applications being filed are ready to go to work. My coworkers are ready to move forward with this carefully planned pathway to market the TactilEar. And, I am

ready to be at your service to most ably serve those with severe hearing impairment and deafness to open their access to the voice of others.

The applications of the device, the market, extends far beyond the borders of the United States. This will be a healthy move for those handicapped and for the economy. Something good like this blesses all. I welcome your support in this endeavor, and I thank you for this opportunity to speak to you today.

[The prepared statement follows:]

STATEMENT OF DENYSE C. DUBRUCQ, ED.D., CHIEF EXECUTIVE OFFICER, EAR THREE SYSTEMS, PROVIDENCE, R.I.

Honorable Congressmen, Let me first define my own involvement in the area of sensory and communication aids for the handicapped. In December, 1981, during the Christmas holidays, I was working on a way to animate Cued Speech for computer use when a more efficient way to code speech just unfolded on the animation paper. This quickly evolved into a wrist-worn device which after two years of full time pursuit is near ready for commercial marketing in mass production. It will present speech in real time from natural speech. It is described as "hearing apparel" worn on the wrist. Interpretation of the code is complete in the tactile sense as the attached study shows. Therefore even the deaf and blind individuals can use it.

To fill the circle, we will be renting and distributing the ConvAid device of Professor Zita Albes which talks for those who cannot speak. In our instructional applications it allows the person to choose the series of words he wants to hear tactilely and have them repeat on call. This builds both listening and speaking vocabulary serving as model speech. With Braille overlays, blind persons without the ability to speak can present oral messages with this device. The ConvAid is presently in production in England and is funded for this production by the British Government.

In the United States, I find the present method of funding the handicapped area preserves the Status quo, preserves the handicaps and the jobs related. I thought that the Small Business Innovative Research Program could cause a change; however, the "peer" reviewers have captured control of it to universities-related activities.

In over $1,000,000 in applied requests for federal support, only $30,000 as a NSF-SBIR grant was awarded.

The chair of the peer review committee for the Deaf and Blind NIH-SBIR proposal was L.D. Braida who heads the MIT Research Team reporting in the 1982 publication as a subchapter entitled "Auditory Psychophysics and Aids for the Deaf; Communications Biophysics chapter; of PR. 122, these grants:

NIH 5-RO1-NS11153-03	1-T32NS07099-01	NSF BNS77-16861
5-RO1-NS10916	1-RO1-NS14092	BNS77-21751
5-RO1-NS12846	2-RO1-NS11680	

How can he allow this era to end? How many persons are being helped? A hand full of research subjects while 11 million wait and of those 66,000 students with severe and total hearing loss remain in special education.

Funding Bill HR 4437 will fund those capable of assisting the vision, speech and hearing impaired individuals. It will pay the winners and performers, not the slaggard.

To bring rapid aid to the situation, I offer to you the opportunity to make an example with Ear Three Systems. We have the talent and the expertise to succeed in preparing for market, mass producing, the TactilEar. It retails for $750 for the device and $200 for the twenty lesson instructional series.

I can solve the problem of hearing loss better than universities because, besides knowing what I am doing and can do, I have the means ready to produce, to meet the needs of the deaf quickly. Working with Ear Three Systems are Digital Equipment Corporation, RCA Corporation, General Electric supplying necessary components. We have the production expertise for both the sound and speech analyzer and the tactile array worn on the wrist. Marketing is progressing to meet the production capacity as is the instruction.

I request that you take this opportunity to portion out this one area of study—measuring private industry capability using Ear Three Systems to solve a major problem today—deafness. Private industry acts faster than universities and therefore can serve more people faster.

Two examples of government sponsorship are evident: First, as mentioned earlier, the British Government financed the production of the ConvAid directly. They are distributing it presently throughout Europe and are in the process of introducing it in the United States, and Ear Three Systems has a role in this process.

Second, in the auto industry, the Chrysler Corporation, a New York Stock Exchange listed business, was given grand support to move them forward. It saved jobs and brings good competitive automobiles to the market.

Ear Three Systems to date has received $30,000 in Federal moneys; has borrowed in venture capital (including interest) $115,000; presently owes $70,000 in bills; and is seeking $3.5 million to launch the TactilEar on the commercial market.

By the end of 1984, with funds, we can have completed our three months of marketing in Rhode Island, our Model Marketing State, and can be starting the national distribution opening ten "ListenEars" per week.

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My choices of initial employees in Rhode Island with their employment security job training applications being filed are ready to go to work. My co-workers are ready to move forward with this carefully planned pathway to market the TactilEar. And, I am ready to be at your service to most ably serve those with severe hearing impairment and deafness to open their access to the voice of others.

The applications of the device, the market, extends far beyond the borders of the United States. This will be a healthy move for those handicapped and for the economy. Something good like this blesses all. I welcome your support in this endeavor, and I thank you for this opportunity to speak to you today.

Comprehension of Vibrotactile, Multi-Stimuli, Coded Speech by Prelingually Deaf Oralist Children

Article by Denyse C. DuBrucq EdD, Chief Executive Officer,
Ear Three Systems, The Calart Building,
400 Reservoir Avenue, Providence RI 02907.

ABSTRACT: Can the phoneme sequences of speech when presented via the TactilEar (a multi-stimuli, vibrotactile device worn on the wrist) be understood as language? The eight prelingually deaf children in an oralist program participating in the first field test of the TactilEar received between two and four and a half hours of instruction. Those 13 - 14 years old attained 50% accuracy at one hour of instruction, and those 3 - 6 in less than two hours. For the tests the coded speech carried the entire speech message.

Viewing the problem of deafness as a condition of inaccessibility to speech and sounds in the environment, development of a means to enable reception of identified sounds by tactile means for those with hearing loss is being carried out by Ear Three Systems. The resultant product is the TactilEar, a multi-stimuli, vibrotactile device worn on the wrist. Results of the first field trial of the TactilEar, research sponsored as a Small Business Innovative Research Grant by the National Science Foundation, is reported here.

The common sensory substitution for hearing loss is visual. Lipreading, Total Communication, sign language, and Cued Speech all require the visual substitution for auditory loss. The phonemic, syllabic coding device of R. Orin Cornett, the AutoCuer, requires visual reception and alignment of the coder with the speaker's lips in order to read the speech message. This puts multiple constraints on the AutoCuer "listener"; however, the wearer does receive fully defined phonemes. (Cornett, 1975; Nicholls, 1979)

In child development, the tactile, visual, and auditory senses all serve major learning functions for the young child. Formal education tends to de-emphasize the role of the tactile sense in favor of the visual sense substituting the picture and text for the object and experience. Children with hearing loss are then operating nearly 100% visually under these circumstances.

With the communication role of the visual sense emphasized greatly in language learning, some of the observational experiences of childhood can be missed. As the researcher taught high school basic math at the Model Secondary School for the Deaf after long experience with 3 - 12 year olds in the Montessori environment, this deprivation was obvious.

Timing increments are far less resolved visually than with the auditory or tactile senses. The sound couplets (a consonant and a vowel sound) signalled in Cued Speech enable the hand movement and its visual recognition to occur in speech cadence. Movies, 16mm with sound track, operate at 24 frames per second or 41.6 milliseconds (ms) per frame. The duration of the "t" sound in speech is 2 - 3 ms, and the "b" and "p" are about

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5 ms. Vowels and sustained consonants as "m", "s", "r" can drag out to 200ms (Marley, 1982). When signalling single phonemes, the eyes would miss some of the phoneme components of speech. Using the visual mode of TactilEar code, animating realtime speech coding using white spots on a black background with 16mm film, viewers could not resolve the short, one frame, sound codes. Also, regarding frequency presentation, observing light emitting diodes (LEDs) driven with varying frequency between 100 and 300 cycles per second (cps) (10 - 3 ms), only continuous light could be perceived, even by one bothered by 60 cps (16.7 ms) flicker of fluorescent lighting.

To spread the reception mode for speech more fairly among the senses, to enable reception by people with both vision and hearing impairment, and to get more information to the person's perception processes, tactile presentation of the speech phoneme code is preferred. The animated patterns of sequential phonemes in speech can be distinguished as can frequency variation between 100 and 300 cps which can trace the pitch variations in speech and music when the tactile sense receives the signals in a properly designed device.

Georg von Bekesy (1967) reports that nerves in the cochlea of the ear receive stimuli at the same frequencies as the tactile reporting nerves in the skin, at between 10 and 400 cps. The mechanism of the ear translates the audio signal frequencies to location-specific areas in the cochlea, thus indicating the sound frequencies by location. This concept of hearing is used in the Saunder's Belt and the Vocoder (Engelmann and Rosov, 1975). The resolution of speech using the 16 - 32 stimuli is not matching that of ear hearing where stimuli (cochlear hairs) number in the thousands.

In design of a tactile device, one must take into account von Bekesy's work on inhibition factors of multiple stimulation. Using two sharpened lead pencils, this can be easily verified. Our work agrees with von Bekesy's requirement for 1/2 inch spacing between tactile stimulators to feel two distinct stimuli. In the TactilEar used in this study, 7/8 inch was the minimal spacing between proximal stimulators. Minimal spacing for infants has not been determined for the lack of testing technique regarding feedback.

THE TACTILEAR PHONEME CODE

The code presents two types of information, the sound identification and the related mouthform, on opposing sides of the wrist. This enables spacial "holographic" tactile patterns with configurations unique to each phoneme in human speech. To add to its information richness, these patterns can be displayed with vibrational frequencies proportional to the pitch or tone of speech or song.

On the "watch side" of the wrist, two columns of four stimulators each distinguish the vowels in one column and consonants in the other. Eight patterns are used in each column: each stimulator singly, 1 - 3, 1 - 4, 2 - 4, and 1 - 2 - 3 - 4. The vowel-consonant groupings are distinguished by column change patterns, and the particular phonemes by location up and down and along the column and the total intensity of the stimulation which is proportional to the number of stimulators in action. It is best interpreted in an analogue fashion rather than digital, mentally.

On the inside of the wrist, a 3 X 3 square matrix defines the related mouthform to the phoneme being presented. This the AutoCuer does not have; however, the Tradoma device (Braida, 1982) does it elegantly. Considering the square matrix as a tic-tac-toe board, winning through the center gives four alternatives. Each direction equates

a consonant-specific mouthform separating, by example, "s", "m", "l", and "f". The single corners and the center represent mouthforms for "e", "a", "o", "r", and "k", with "o" being the center. The consonants give more intense signals with a vector direction to the pattern. The single signals give an imbalancing or centering of the square. With these two matrices aligned parallelly on the wrist, the animated signal is believed to be clearly readable with experience.

Drivers for the TactilEar include manually presented speech code using a keyboard, animated speech using 16mm film with a screen imbedded with photodiodes which drive the tactile stimulators, and the Marley sound and speech analyzer which is presently in the last stages of development. The experiment reported here employed manually coded speech.

THE EXPERIMENT

Eight children enrolled in the Oralist Program in the Fairfax County (Virginia) Public Schools who were classified as prelingually deaf by their parents served as subjects for the experiment. Four were in the intermediate school, 7th and 8th grades, and three were in preschool, and one in first grade. One instructor was used for all.

Instructional sessions were given on 18 consecutive school days in small rooms provided for the purpose within the two schools. Each child was individually instructed and tested before and after each instructional session. The 13 - 14 year olds had 25 minute sessions, allowing five minutes per test and fifteen minutes for instruction. The 3 - 6 year olds had twenty minute sessions, thus reducing the instructional time to ten minutes.

Instructions consisted of presenting vocabulary words. Initial word groups had single syllable words represented by pictures. Each group had a single vowel with varying consonant patterns. The three groups had vowel sounds of c<u>a</u>t, t<u>oe</u>, and k<u>ey</u>. Eight or nine words were in a group as "boat, bow, bowl, door, four, go, hoe, toad, toe". Each group was presented twice, once tactilely only and once with a visually coded speech display added to the presentation. To make double word groups, the numbers one to six were presented combining them with any of the 26 pictured vocabulary words. For triple word groups prepositions were added and illustrated by the placement of the number in relation to the pictured object, as, "<u>five on</u> the <u>cat</u>" (underlines show required choices). This series comprised the first twelve lessons and were used with both groups of subjects. The younger children had great difficulty so each group was given a different experience for the last six sessions.

The last six sessions for the intermediate school youngsters provided a change of vocabulary to colors and geometric shapes. For the younger children, seven real objects were used including, "ball, bow, box, car, doll, pen, pencil". Illness and field trips reduced the number of sessions for these younger children.

Vocabulary word presentation was by picture, number, placement, and object with lipread word presentation followed by the phonemically coded word using either tactile only or tactile and visual display.

TESTING

ONLY THE MANUALLY CODED WORD SERVED AS THE STIMULI IN TESTING. During the first twelve sessions some of the tests were tactile coding only, others tactile and visual. The last six lessons had tactile only testing. All subjects used the same TactilEar armband.

Testing apparatus besides the manually driven TactilEar includes a floormat divided longwise with a ribbon, card markers to identify subject, date, tactile or tactile-visual display, and nine selected pictures, and when needed the numbers on cards for one through six. To record test performance for delayed grading, an instant film flash camera is used.

As the six test items were sequentially coded to the subject, the subject would choose the appropriate picture and place it on the right side of the ribbon on the floormat below the date -subject information. With multiple word work with numbers, the number and its placement would be added to the picture. After the test items were complete, the test item lists presented on cards with large print would be placed beside the subject's answers and the picture taken.

Test content differed between the pretest and posttest.

Pretests - The first three pretests tested the subject's ability to read, read lips, and interpret pictures by matching associated items as "socks" and "shoes". At the fourth session, each subject had been presented with all 26 pictured words so nine were selected from the field of 26 items and the test consisted of six of those. These tests tapped long term retention.

Posttests - Posttests included items from the immediately preceding instructional session and tapped short term recall. The 13 - 14 year olds consistently had six items per test including multiple word groups as "Four over the bowl" as one test item. The 3 - 6 year olds were overwhelmed by nine items, so in the second six sessions were given fewer to choose from and fewer test items. In the third six sessions, seven objects were used and four or five items were used in the test.

RESULTS

Subject performances on tests are compiled in Table 1 for the intermediate school youngsters. Scores are given in one place decimals with a perfect score being 6.0. The younger children's scores are given as percentages because the number of items varied. The first three pretests for related skills were 100% for each test for all intermediate school youngsters, but varied among younger children, so are provided in Table 2 with other test information. Their performance with pictorial cards was so poor, their number of correct answers for the total number of tests is given as a raw score. Total time of instruction is included with the score data on both tables.

Two external factors caused variation in intermediate youngsters' scores: the refusal to work with the color series though there was no color-blindness among subjects, and, performance in the last session which was diminished by the anticipated school event occurring as soon as the session was over.

To fairly compare performance of the younger children with the intermediate school youngsters, the latters' scores given as percentage correct between 1:15 and 1:45 hours of instruction are 51%, 78%, 70%, and 63% respectively, given in order of each youngster's listing in Table 1. This is the time the children started using the objects as test items.

The children had difficulty working with fields of eight or nine items. They could not complete a six item test. Numbers for three of them were something to order, not to identify. And the prepositions were beyond their understanding. The second week and the first half of the third, the research design was in shambles, but on the entry of objects to represent the words, adherence to the research design returned. For this reason, reporting of test data is limited compared to that for the intermediate school youngsters.

Table 1. Intermediate School Youngsters' Test Scores with 6.0 a Perfect Score

Subject			Score Average (Number of Tests)						
Age	Sex	Instr. Hours	All Tests	Single Word Pretest/Posttest	Double Word	Triple Word	Color	Shape	Color & Shape
13.5	F	4:00	2.62(30)	1.8(8)/2.8(5)	2.6(3)/3.4(5)	-/3.9(2)	2(2)/3(2)	-/3(1)	1.5(1)/3.5(1)
13.5	F	3:45	5.07(27)	4.5(6)/4.5(5)	5.6(3)/5.1(4)	-/5.2(2)	6(2)/6(2)	-/6(1)	4.5(1)/5.5(1)
14.5	M	4:00	2.98(29)	2.9(8)/3.0(7)	2.8(2)/5.0(4)	-/4.5(1)	1(2)/1(2)	-/6(1)	1.0(1)/0.5(1)
13	M	4:30	2.89(33)	2.6(9)/3.9(7)	4.2(3)/4.6(5)	-/4.0(2)	0(2)/2(2)	-/6(1)	1.0(1)/2.0(1)
Weighted Averages:			3.39	2.8/3.5	3.9/4.5	-/4.4	2.3/3.0	-/5.3	2.0/2.9

Mono-syllable and Multi-syllable Test Performance Excluding Color and Color & Shape Tests

Mono-syllable Test Average: 3.1

Multi-syllable Test Average: 4.4 (This catagory includes the Shape Test.)

Probability of one correct answer on six item test with nine choices with a diminishing field of answers is 0.6.

Table 2. Preschool and Primary Children's Test Scores in Percentage

Subject				Percentage Correct (Number of Tests)					Early Session Scores	
Age	Sex	Instr. Hours	Time with Objects	Objects: Pretest	Posttest	Speech Reading	Picture Matching	Reading	Total Correct	Tests
4	M	2:00	0:40	31% (3)	50% (4)	100%	100%	33%	11	13
6	F	2:10	0:20	75% (1)	50% (2)	100%	100%	100%	29	19
4.5	M	2:30	0:40	33% (3)	40% (4)	100%	100%	33%	16	18
3	F	2:10	0:40	50% (3)	53% (4)	67%	67%	0%	23	17

The test scores as percentage represent the proportion correct of four or five test items with a field of seven objects to choose from with a diminishing field of choices.

Scoring of all tests was done from the instant photographs by the instructor and the researcher. Agreement between scorers was 96.2%. The discrepancies were resolved before reporting. This percentage represents ten tests scored containing any discrepancy of the 262 tests scored.

A paired t-Test on early and late sums for all eight subjects are: for early, 1.88(SD=1.40), and late, 3.04(SD=1.29), giving a t-Value of 3.26(Df=7), p<.01. Therefore learning to listen with the TactilEar code did occur.

DISCUSSION

Eight prelingually deaf children ages 3 - 6 and 13 - 14 years did use the phonemic code of the TactilEar successfully to "listen" and understand the coded single word, and, for the older youngsters, up to triple word series. Scores being higher for multi-syllable items (4.4) than for single syllable items (3.1), shows promise for the TactilEar in running speech reception.

The manually coded speech can be somewhat slower than normal speech, but with so much variation in pronunciation speed in the United States among individuals, among dialects, and among circumstances, one could fairly say that manually coded speech could be as extended as a factor of two of relaxed, normal speech. In the planned series of twenty half-hour sessions with two major listening practice tools for vocabulary building, that the manually coded speech may take the same portion of time in these lessons as was provided in this research.

Compared to reported vocabulary learning times for methods of deaf communication, this meager exposure to a new communication form is remarkably fast for learning to recognize words and word groups with meaning. The most comparable time factor study is Oller (1980) who, in one to two hours of instruction with teenage deaf subjects using the Vocoder and lipreading, was able to have all subjects reach 75% accuracy in distinguishing between hard to lipread word pairs. The probability of one correct answer per item is 50% in this case.

In this study using the TactilEar code only - NO LIPREADING - the average test scores for the time interval 1:00 - 1:45 total time is 59% for these teenage subjects and for 2:00 - 2:45 is 67%, these scores including 32 tests per increment. Probability of one correct answer on the six item test is 0.6 and the tests included a 37 word vocabulary during those time increments.

What is in the code that mades it so readable? Unambiguously presented and fully defined speech sounds.

Similar speech recognition has been found with some subjects with Cued Speech which does, when the speaker's face is in view and the person Cues his or her speech or the prototype AutoCuer is used, fully define the speech sound sequences.

With the promising performance of subjects in this research and because hearing impaired, deaf and deaf-blind individuals can use the TactilEar, its development should be supported. Its design lends itself to quantity production and distribution with required instruction - a planned twenty lesson series.

Perhaps prelingual deafness will be no more a threat to the progress and quality of life of the individual in the future than near-sightedness is today.

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Manufacturing Company, developer of the TactilEar; and John Marley, President, Phonetigraphics, Inc., developer of the sound and speech analyzer driving the TactilEar; to Fairfax County School staff especially Dr. Don McGee and Dr. William Griffith; to my research consultants: Prof. Michael B. Miller, Gallaudet College; Robert B. Alexander PhD, Clinical Psychologist, Chester, Virginia; and Professor Herman Epstein, Brandeis University for their able coordination in carrying this research to completion.

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This Monograph was prepared February 23, 1984, as part of the testimony of Danyse C. DuBrucq, EdD before the Health Subcommittee, the Ways and Means Committee, of the United States House of Representatives, Washington DC 2:00 February 27, 1984.

Dr. DuBrucq is a proponent of Rep. George Brown's bill, H.R.4437 and of Sen. Spark Matsunaga's bill, S.1115, both of which increase availability of devices for those with sight, hearing, and speech losses.

Mr. MATSUI. Thank you very much. I would like to thank you for your testimony. We appreciate it.

The last witness today will be John Doyle Elliott, director and manager of the Townsend Plan National Lobby.

Your written testimony will be received without objection for the record, but you may summarize it or read it. Thank you.

STATEMENT OF JOHN DOYLE ELLIOTT, DIRECTOR AND MANAGER, TOWNSEND PLAN NATIONAL LOBBY

Mr. ELLIOTT. Mr. Chairman, I represent the Townsend Plan movement from way back in its beginnings up to today. And I react to all these things in the light of the principles underlying the Townsend Plan, which started the whole affair in the first place.

We offer support. We approve of H.R. 4437 for a very simple reason. That it is designed to start insurance that will tend to alleviate, put down the effect of these disabilities. Not just to help out a little bit. Now, medicare is actually national health insurance. But medicare does not supply its benefits as the rest of the benefits under social security are supplied. Medicare could not do that. They couldn't possibly say, now, Mr. Jones, you have been quite successful in your earnings; therefore, you will get a whole appendectomy, for example. Mr. Smith, your earnings have been scant, and we can only allow you half an appendectomy.

In the nature of the situation, medicare health insurance, they just couldn't say it that way. So medicare is a step in the right direction from the point of view of the Townsend movement right from the start.

Now, there is another side to all of this that I think is very much in line to be brought up on top of the table. Since the early years of this century, Mr. Chairman, members of the committee, we have been tolerating in this country the unemployment of employable people. There is no second of time ever did or ever will come back to be used over again. The toleration of this thing, it is the cause, it is the occasion for all of our economic problems. There is no other loss in human history that begins to match our failure to employ employable people right here in the USA.

The two periods in this century when we did alleviate that we did it by participating in the emergencies of World War I and World War II. And following each of them we went into depression, and war brought us out of both of them. In the early years, the first decade of this century, we faced what threatened to be the biggest economic default in all history. They called them panics then, not depressions. But World War I brought us out of it. We retired an army of perfectly healthy, mentally and physically, almost entirely, men out of the economy. If they were farmers, they weren't farming when they became soldiers. If they were shoemakers, they were not making shoes, Mr. Chairman. And without them we created more millionaires than ever heard of, or dreamed of, up to that date in history.

We repeated the same thing all over again and led into the Great Depression and World War II, which got us out of it. We took some 16 million citizens out of the economy—healthy mentally and physically—between the ages of 18 and the lower middle ages. Over 16

million of them. And I say again, if they were shoemakers, they weren't making shoes, those soldiers. Nor if they were coal diggers, they weren't digging coal. If they were farmers, again, I say they weren't farming. They were out of it. Yet, they were the most employable people among us all. Yet, they were retired for the sake of taking care of World War II.

Now, if we look at the picture, we will realize why we haven't heard about it. It would be almost impossible to research it in exact detail or anything resembling it. But it is right there, square and straight, on the face of history—for anybody to see. We have been failing to employ employable people; and we are doing it right now, on a growing scale. It stands in the way of every possible success and is the fertilizer for the United States being unable to perform as it should be performing, not only domestically but internationally, as well.

I make no apology for my indictments.

Thank you.

[The prepared statement follows:]

STATEMENT OF JOHN DOYLE ELLIOTT, DIRECTOR, TOWNSEND PLAN NATIONAL LOBBY

Mr. Chairman, the Townsend Plan has consistently endorsed complete national health insurance in the United States ever since adopting its resolution in 1946. Its coverage—as yet incomplete—is a mightly start on the prime road to fullest justice and health—life its very self. Medicare is, in fact, national health insurance. Our unqualified prayer is its full expansion to fullest coverage of human health.

We therefore happily welcome H.R. 4437 to provide for Medicare benefits to provide for devices and other means to overcome and/or lessen the disabling effects of physical and mental causes. It proposes legislation reflecting the difference between Medicare and the rest of Social Security's aims and lack of them. I have characterized Medicare as the first "right" just thing yet legislated under Social Security, namely: Medicare does not say to one person, "Your earings have been generous, plentiful; so, you get full treatment, to a whole appendectomy", for example; while it informs the next applicant, "Your earnings have been scant; so, you are entitled to only half (!!!) an appendectomy!" Yet, that's how we meet the benefit entitlement under the rest of Social Security! The more prosperous person gets the most; and where the need is the most, the benefit is the least. That's how Social Security benefits life's necessities, food, shelter and clothing!

H.R. 4437 seeks as fully as possible to overcome disabilities by the most effective benefits. And so does the Townsend Plan; for fifty years! Hence why we support H.R. 4437's proposal of a benefit as high as $5,000 per year benefit to overcome disabilities and a limit of $15,000 in the course of any five consecutive years.

HEALTH AND SCIENCE

As in other fields of progress, discovery, invention—science from space, right down here to health, life itself is steadily growing, expanding—surgical space, right down here to health, life itself is steadily growing, expanding—surgical operations on people lately revealed costing $75,000 to $90,000 and no end in sight.

At the same time people—human beings—facing this winter's storms without any shelter for the night, lacking anything like protecting clothing, without any source of heat, or the price of food—in fact lacking everything needed!!

H.R. 4437 is right on the bull's eye. As was the Townsend Plan, so long ago! We must stop having employable people unemployed. Why? Because there never has been—and there is never going to be—one single second of time that is going to come back to be used again! And the seconds and the years of unemployment of employable poeple has been fact since the earliest years of this century—the nearest exception being during the two World Wars. Unemployment of employable people is the worst of all economic losses. Stupid!

Science is making it possible by revealing discoveries revealing an expanding stream of learning how we can increasingly protect human life from encountering the evils that render so many people unemployable. disabled—ever increasingly, science is making this wonderful achievement grow, grow, grow.

We ought to start arranging for the people who are unemployed, but who do not have jobs because progress has rendered their jobs no longer effective—some by being replaced by robots—let us fix it for these people to learn new jobs—like jobs involved in public works—our sagging public works.

Above are our reasons for urging promptly the adoption of H.R. 4437 and the perfection of our whole misguided Social Security system—except for Medicare!

Mr. MATSUI. Thank you very much.

Mr. ELLIOTT. No second ever comes back to get reused over again.

Mr. MATSUI. Thank you. I would like to thank the ladies and gentlemen who appeared and testified today. We appreciate your testimony and involvement very much.

With that we will now adjourn this meeting. Thank you.

[Whereupon, at 3:50 p.m., the hearing was adjourned.]

[Submissions for the record follow:]

STATEMENT OF THE AMERICAN FOUNDATION FOR THE BLIND, GLENN M. PLUNKETT, SPECIALIST IN GOVERNMENTAL RELATIONS

The American Foundation for the Blind joins with other organizations, groups and individuals concerned with those who have visual, speech and hearing impairments in advocating medicare/medicaid coverage for sensory aids and devices to assist them in becoming productively employed and to enhance their independence and educational opportunities.

The American Foundation for the Blind is a national, non-profit organization which provides both direct and technical assistance services to blind and virually impaired persons and their families, professionals in specialized agencies for the blind, community agencies, organizations, schools, and corporations. Direct services include information and referral to blind persons, their families and professionals, special consumer products, a travel identifcation service, and general educational materials. Technical assistance services include training, consultation, professional publications, public information, and social and technological research.

THE SEVERELY VISUALLY IMPAIRED POPULATION

The National Society to Prevent Blindness (NSPB) estimates that there are some 500,000 persons in the United States who are legally blind. The definition of blindness used in arriving at this estimate is the same as that used in section 216(i)(1) of the Social Security Act; i.e., central visual acuity of 20/200 or less in the better eye with correcting glasses, or a contraction in the field of vision to 20 degrees or less in the better eye if central visual acuity is better than 20/200. The prevalence rate of legal blindness is 2.25 per 1,000 of population.

Based on data from its 1977 health interview survey, the National Center for Health Statistics of the United States Public Health Service estimates that there are some 1.5 million civilian noninstitutionalized individuals in the United States who have severe visual impairment. The definition of severe visual impairment used in reaching this estimate was inability to read ordinary newspaper print with the aid of correcting glasses. The prevalence rate is 7.0 per 1,000 of population for all ages.

The National Center estimates that 142,000 of these individuals are under age 45 (prevalence rate 1.0 per 1,000), that 259,000 are between the ages of 45 and 65 (prevalence rate 6.0 per 1,000), and that 990,000 are 65 and older (prevalence rate of 44 per 1,000).

No one knows the exact number of totally blind individuals in the United States. Authorities associated with rehabilitation centers for the blind and other agencies providing direct services to blind persons estimate that between 12 and 20 percent of the legally blind population have no useful vision. Therefore, we can assume that a maximum of nearly 100,000 persons in the United States are totally blind or have only light perception. The rest have varying degrees of residual sight, the handicapping effects of which may be minimized through use of sensory aids and permit the individuals to be productive workers.

The number of working age individuals who are visually impaired and covered under medicare because they receive SSDI is very limited. Based on estimates from the Social Security Administration, there are approximately 84,000 disabled individuals under age 65 receiving SSDI benefits who are blind/disabled. We do not know the number of those whose incomes are at or below the poverty level but since the

average disability benefit payment is $441.00, and the majority of the recipients are dependent upon their benefits, there is not much opportunity for blind/disabled individuals to purchase expensive telesensory equipment to assist them in employment or otherwise. Out of the 84,000, the number that may be able to make use of sensory equipment for employment purposes is probably very small since the average age for disabled beneficiaries is 52.9 for men and 53.7 for women (social security bulletin, Annual Stat. Sup. 1982 page 154). Considering that the percentage distribution of the disabled recipients (men) is 4.1 under age 30, 9.6 between 30-39, 6.0 between 40-44, 8.9 between 40-49 and the rest over age 50, employment opportunities would be very limited. The percentages for women runs about 1% less for the age categories as shown for men.

We do know from SSA statistics (social security bulletin, Jan. 1984 pages 19-20) that 36 percent of the disabled/blind recipients of supplemental security income also receive SSDI payments. Since there are 79,061 blind individuals who receive SSI and of these approximately 22,000 are over age 65 and approximately 7,000 are children of various ages—this leaves about 50,000 in the SSI universe and of that number about 18,000 have SSDI benefits and therefore medicaid coverage. Recognizing that the SSI payments are below the poverty level, it is obvious that those individuals cannot afford to purchase, rent or maintain equipment or pay for training in its use.

We want to underscore one of the most important aspects of the proposed legislation ". . . training in the use of such aids". Unless training, and re-training as necessary, is made a basic requirement in the legislation, and in the regulatory requirements, benefits are not likely to accrue to the target population. It would be desirable to amend the proposal to state that medicare payments would not be made for the purchase of any of the devices contemplated under the act unless and until an established training program in the use and application of the product had been completed.

The proposed legislation would need amendments to permit payments for the various therapeutic and training disciplines necessary to implement the program.

We also believe that the repair and maintenance of high technology sensory equipment should be a coverage item since such items could not be borne by an individual trying to escape dependence and poverty through use of the covered equipment.

We are cognizant of the problems in medicare/medicaid funding and of the need to create cost offsets where possible in any new program coverage such as proposed in H.R. 4437. However, this initiative may very well display the advantages of providing aids and devices of various types and levels of sophistication to the handicapped under medicare regardless of age in that such devices may delay or prevent more costly care in institutions and enhance the quality of life in the home and in the community for those in need of sensory aids. These may be of low cost, non-electronic types as well as the more highly sophisticated types. We hope that the Congress will address that possibility as the medicare funding problems are overcome and program improvements are made.

Payments for aids and devices through the medicare/medicaid programs would have far-reaching and long-term beneficial effects on the individuals and on the budget. The Office of Technology Assessment in its May 1982 report (Technology and the Handicapped) pointed out that the financial aid available for the purchase of sensory and communications aids was generally limited to the lower cost devices: "Use of such a criterion may fail to identify instances when a greater initial investment might result in a decreased long-term cost and greater functional ability for the individual involved." OTA further observed that ". . . a significant effect of the current system is that in the short-term funds may be saved while in the long-term or greater amount of total funds is expended in, for example, income maintenance payments or institutional expenses." It is apparent that many blind and other disabled people cannot afford the cost of sensory and communications aids needed for employment or education; that alternative financing for such equipment is inadequate, and that reimbursement under the medicare/medicaid programs is necessary to help blind and other disabled persons to meet the high cost of these aids. We urge Congress to consider the other financing alternataives suggested in the OTA report as well as the coverage in H.R. 4437. These include low interest loans, loan guarantees, and tax incentives for purchase of senior and communications aids.

We also urge Congress to assess the very fine distinction being made in the medicare reimbursement program between aids and equipment that are considered "medically" required and the non-reimbursement of other aids, devices, therapies, and training that would ameliorate disabilities and which would have a very beneficial effect on the individual. It is our considered opinion that blindness and disability are medical problems which can be ameliorated by aids and equipment. Nothing

in the law prohibits reimbursement for sensory and communication aids. OTA found however, that requests for reimbursement for this equipment are often denied because the devices are not considered to be "medically necessary" (page 4 of the May 1982 report). The discrimination exists because the primary focus of the medicare program has been upon medical problems and not a concurrent emphasis on amelioration of disabilities. The OTA report emphasizes that ". . . a connection needs to be made in these programs between paying for . . . technologies and the potential independence or productivity of disabled people".

STATEMENT OF THE BLINDED VETERANS ASSOCIATION, THOMAS H. MILLER, NATIONAL PRESIDENT

I am very pleased to submit this statement on behalf of the Blinded Veterans Association in support of H.R. 4437, the Handicapped Independence Act of 1983.

The BVA is a non-profit organization founded in 1945 by a group of veterans blinded during World War II. We are chartered by the U.S. Congress as the official representative of blinded veterans.

The BVA is the only organization of its kind. It is the only organization with programs and activities that emphasize seeking out blinded veterans where they live. It is the only organization committed to reaching out to blinded veterans to offer support and assistance that is needed. Programs offered by the BVA encourage blinded veterans to assume an active role in life. The BVA helps blinded veterans obtain the benefits for which they are eligible, which not only include disability compensation and pension, but also rehabilitative training, prosthetic and sensory aids, and medical treatment. The BVA also conducts a program to help blinded veterans develop satisfying careers. We provide assistance from resume preparation to contact with prospective employers. We conduct an information program and publish a bimonthly publication for blinded veterans which is printed in large type and available on recorded discs.

Our mission is a positive one. It is the very nature of this mission which merits the BVA the distinction it has earned throughout its 38 year history. In the course of serving blinded veterans with such distinction, the BVA also has developed an expertise that cannot be matched or even rivalled by any other organization, whether it be in the public or private sector.

What we have proven over the years is that blinded veterans with assistance and support can adjust to their blindness—that blinded veterans can develop a renewed sense of strength and courage—the same strength and courage that compelled us to serve our nation, especially in times when our nation needed us to preserve its history and its heritage.

H.R. 4437, the Handicapped Independence Act of 1983 would provide Medicare and Medicaid coverage for sensory and communication aids. The Blinded Veterans Association supports passage of this legislation. We want to take this opportunity to thank Representative George Brown (D–CA), Robert Matsui (D–CA), George Miller (D–CA), Cecil Heftel (D–HI), and Ed Zschau (R–CA), sponsors of H.R. 4437. By providing Medicare and Medicaid coverage for sensory and communication aids, this equipment would be more readily available to persons with visual impairments, severe hearing problems, or speech difficulties. These aids would provide a means to strengthen or replace a sense that has been severely diminished or lost.

With the exception of the cassette tape recorder (which is used by many blind people today), most sensory and communication aids required by the blind are prohibitively expensive. Inordinate costly research and development expenses mandate the high prices imposed by manufacturers for such equipment. The situation is even more precarious for such manufacturers because the consumer market is small and prices cannot benefit from mass production.

Unfortunately, a high percentage of disabled people also have low income levels. A disproportionate number have incomes below the poverty level. In many instances, private resources or insurance are exhausted on basic medical needs associated with the disabling condition. As a result, few blind and disabled persons can afford to purchase these useful tools which could help them find worthwhile employment and lead to a more independent existence.

H.R. 4437 would provide for uniform guidelines throughout the country. Currently, reimbursement procedures for sensory aids for the blind vary from state to state. Also, the Medicare and Medicaid systems put undue burdens on blind Americans to prove that sensory devices are medical necessities, and in most cases, deny reimbursement, despite the fact that such devices are essential for the enrichment of a blind person's daily living. Third party payment rarely deems sensory aids as medi-

cally necessary and therefore not reimbursable as Durable Medical Equipment under Medicare provisions.

The BVA believes H.R. 4437 would enhance the availability of sensory and communication aids to blind Americans. Although Medicare, Part B, (which establishes reimbursement procedures) does not specifically exclude coverage of communication devices, this effect is achieved by the random denial of communication devices as medical necessities. Medicare and Medicaid should recognize providing sensory aids to enhance daily living as reimbursable expenses.

The cost to provide these aids to disabled people through Medicare and Medicaid is the main obstacle to passage of H.R. 4437. Tlthough the initial expenditure to provide these aids and appliances to disabled people would be substantial, passage of this bill would result in an economic benefit to the nation as well as independence for disabled Americans. These sensory aids help increase the communications capacity of many disabled people which would lead to broader educational opportunities as well as gainful employment. Savings that would offset the costs of implementing H.R. 4437 would be reduced welfare payments, reduced SSDI payments, reduced Medicare and Medicaid payments, and increased Federal, State and local tax revenues.

However, financial considerations should not be the only reason that sensory aids are made available to disabled people. Because of age or severity of their disability, many will not seek employment. Nonetheless, the quality of their lives could be enhanced by access to these sensory aids. This is a noble goal and an achievable objective.

We encourage this subcommittee to approve passage of H.R. 4437 and we thank you for the opporunity to present this statement in support of H.R. 4437

THE CENTER FOR THE PARTIALLY SIGHTED,
Santa Monica, Calif., March 5, 1984.

Mr. JOHN J. SALMON,
Chief Counsel, Committee on Ways and Means,
Washington, D.C.

DEAR MR. SALMON, Thank you for this opportunity to submit written testimony to your Subcommittee on Health of the Ways and Means Committee in support of H.R. 4437, the "Handicapped Independence Act of 1983."

My name is Samuel Milton Genensky. I earned a Ph.D. in Applied Mathematics, and I am the Executive Director and President of the Center for the Partially Sighted, a nonprofit, public benefit, tax-exempt California corporation that provides a full range of visual rehabilitatives services to partially sighted people of all ages. The Center is located at 919 Santa Monica Boulevard, Suite 200, Santa Monica, California 90401. Each year the Center gives direct assistance to some 900 patients, primarily Southern Californians, and information and referral by mail and by phone to thousands of other partially sighted people throughout the United States.

My remarks will be confined primarily to making a case for providing low vision visual aids to the more than 1.04 million Americans who are both partially sighted and at least 65 years old. However, my concentration on this portion of the handicapped population should in no way be construed to mean that I am not in favor of assisting the other handicapped persons covered by the legislation. My area of expertise includes the partially sighted and not the other handicapped persons, and that is the sole reason that I have chosen to confine my advocacy to that portion of the handicapped population to be covered by H.R. 4437.

I believe that it is in order for met first to define whom I refer to when I use the term "partially sighted." I define the partially sighted to be those people whose best corrected visual acuity in their better eye does not exceed 20/70, but is better than light projection or light perception, and to also be those people whose visual field has a maximum diameter that does not exceed 30 degrees, even if the best corrected visual acuity in their better eye does exceed 20/70. A less precise but perhaps a more understandable definition of the partially sighted is one that states that persons are partially sighted if, even with the help of ordinary eyeglasses or contact lenses, they are *not* able to read newspaper column type at normal reading distances of from 10 to 16 inches, but they are able to see more than light and tell the direction from which that light is coming; and persons are also partially sighted if their visual field does not fill out the area that would be occupied by a 10 inch-diameter dinner plate viewed straight on at a distance of 18.7 inches.

My research indicates that in 1980 there were 1.95 million partially sighted people in the nation and that, as pointed out earlier, more than 1.04 million of them were at least 65 years old. It also showed that more than 19.8 percent of the partial-

ly sighted in that age category are also legally blind, and that 78.8 percent of the legally blind in this age range are partially sighted. Our Center and other persons and organizations serving the partially sighted have found that nearly all partially sighted people, whether they be legally blind or not, with a) the help of appropriate visual aids, b) training in the use of those aids, and c) the motivation to utilize them, can perform such sight-intense tasks are 1) read ordinary inkprinted materials, 2) write with a pen or pencil 3) view a chalkboard and take notes on or copy what is seen, and 4) move about alone, in even and unfamiliar environment, without the help of a guide dog, a cane, or a fully sighted guide. Therefore, I believe it is fair to conclude that the vast majority of the partially sighted and, yes, the vast majority of the legally blind, are not blind.

I myself am partially sighted anbd I have been since shortly after birth. I have no vision whatsoever in my left eye and 20/1000 in my right eye. More than 70 percent of the legally blind have better visual acuity than I have, yet I have always lived a sight oriented life.

At our Center we have found that nearly all the older Americans who are partially sighted and who come to us for help (better than 65 percent of the people we serve) want to be viewed as persons with valuable remaining eyesight and not as blind persons. Further, they want to use their remaining eyesight to function as visually and as independently as possible. Further, they have no desire to be confined to a nursing home any sooner than is absolutely necessary. I am pleased to report that many of these people are able to maintain their independence because of what we have taught them about the value of their remaining eyesight, and because of the visual aids we have prescribed for them and taught them how to use.

Unfortunately Medicare does not cover the cost of low vision examinations, low vision aids, training in the use of those aids, psychological counseling, orientation and mobility training, and instruction in skills needed to live indcpendently in the home. These are services that these severely visually impaired people desperately need and that many of them simply cannot afford to pay for. We have gone to the private sector seeking support to assist us in helping these deserving Americans. I am pleased to report that we have had some success in doing this, but the job is just too big for the private sector to support by itself. Help is needed from the federal government, and H.R. 4437 will provide that help at least as regards the visual aids themselves. I urge you and your colleagues to support and approve H.R. 4437. Its passage and its funding will help thousands of partially sighted older Americans to maintain their independence. In so doing, they will avoid for years premature confinement in nursing home environments, that, in the long run, would be much more burdensome on the American taxpayer than provision of the monies needed to fund the program described in H.R. 4437.

Enclosed you will find a brochure that decribes this Center, 1980 population statistics, by age group, of various categories of visually impaired persons, a list of definitions for the terms used in those population estimates, and a brief biography of the writer of this letter.

Please feel free to include this letter and any of its enclosures in the written report of your Subcommittee.

Thank you for giving me and other concerned Americans the opportunity to express our support of H. R. 4437.

Very sincerely,

SAMUEL M. GENENSKY, Ph.D.,
Executive Director/President.

Enclosures.

SUMMARY OF NATIONAL DATA ON VARIOUS COMPONENTS OF THE VISUALLY IMPAIRED POPULATION—1980

Age	PS	PS-LB	LB	LB-FB	FB
0–4	5,500	4,400	1,800	1,100	700
5–19	123,900	99,300	37,500	24,600	12,900
20–44	328,500	263,300	89,700	65,200	24,500
45–64	444,000	355,900	117,200	88,100	29,100
65–74	338,800	271,600	87,400	67,200	20,200

SUMMARY OF NATIONAL DATA ON VARIOUS COMPONENTS OF THE VISUALLY IMPAIRED POPULATION—1980—Continued

Age	PS	PS-LB	LB	LB-FB	FB
75–84	371,400	297,700	93,100	73,700	19,400
85+	334,200	267,900	82,700	66,300	16,400
Total	1,946,300	1,560,100	509,400	386,200	123,200

PS—Partially sighted.
PS-LB—Partially sighted but not legally blind.
LB—Legally blind.
LB-FB—Legally blind but not functionally blind.
FB—Functionally blind.

DEFINITIONS

(1) *Totally blind:* Persons are totally blind if they cannot visually detect light with either eye.

(2) *Light perception:* Persons have light perception if, with their better eye, they can only see light, but are unable to tell the direction from which the light is coming.

(3) *Light projection:* Persons have light projection if, with their better eye, they can only see light *and* determine the direction from which the light is coming.

(4) *Functionally blind:* Persons are functionally blind if they are either totally blind or if they have at most light projection.

(5) *Legally blind.* Persons are legally blind if the best corrected visual acuity in their better eye does not exceed 20/200, of if the maximum diameter of their visual field does not exceed 20 degrees even though the best corrected visual acuity in their better eye exceeds 20/200.

(6) *Partially sighted:* Persons are partially sighted if the best corrected visual acuity in their better eye does not exceed 20/70 but is better than light projection, or if the maximum diameter of their visual field does not exceed 30 degrees even though best corrected visual acuity in their better eye exceeds 20/70.

(7) *Partially sighted and legally blind:* Persons are partially sighted and legally blind if they are legally blind but are not functionally blind.

(8) *Visually impaired:* Persons are visually impaired if they are either functionally blind or partially sighted.

(9) *Partially sighted and not legally blind:* Persons are partially sighted and not legally blind if they are visually impaired but are not legally blind.

(10) *Fully sighted:* Persons are fully sighted if they are not visually impaired.

Dr. Samuel M. Genensky is the President and Executive Director of The Center for the Partially Sighted, Santa Monica, California. He himself is severely visually impaired as a result of a hospital accident when he was just a few days old. Despite his visual loss (no sight in left eye, 20/1000 in right eye), Dr. Genensky received a B.S. degree in Physics magna cum laude from Brown University in 1949, an M.A. degree in mathematics from Howard University in 1951, and a Ph.D. degree in Applied Mathematics from Brown University in 1958.

Dr. Genensky is also a consultant at the Rand Corporation in Santa Monica. In 1965, he and his Rand colleagues began their research on problems of the partially sighted. At that time he was a full-time member of the Rand staff. His broad range of research efforts related to that population includes pioneering work on visual aids, architectural barriers, and visual environmental adaptation problems. Prior to his work on behalf of the visually impaired, he played a key role in the development of Rand's early efforts to apply its military know-how to nonmilitary national problems, particularly in the area of health.

Dr. Genensky is a Visiting Lecturer in the UCLA School of Medicine, Department of Ophthalmology. He is also a member of the Board of Trustees of the Southern California College of Optometry, and is the founding president and a current board member of a national advocacy group, the Council of Citizens with Low Vision. In recent years he has served on advisory groups to a number of important organizations, including the California Department of Rehabilitation, the American Foundation for the Blind, and the 1979 National Implementation Advisory Committee of the White House Conference on Handicapped Individuals. He is a member of the Society of the Sigma Xi, the American Association for the Advancement of Science, and the American Mathematical Society.

In addition, Dr. Genensky has received numerous honors and awards. In 1980 he was given a "Maintstream Milestones" award by the Los Angeles Junior Chamber of Commerce and the Los Angeles Major's Committee on the Handicapped. He re-

ceived the honorary degree of "Doctor of Humane Letters in Optometry" from the Illinois College of Optometry in 1979, and in the same year he was given an award for distinguishing services in human relations from the National Conference of Christians and Jews. In 1972, Dr. Genensky received the Paul Yarwood Award from the California Optometric Associaton for his contributions to visual research, and he also earned an award for meritorious service from the South Bay Mayor's Committee on Employment for the Handicapped. In 1971 he was made a Fellow of the American Academy of Optometry, a distinct honor for a person not in the optometric profession. He is considered a world-renowned authority on the subject of visual impairment and low vision aids. He has made numerous presentations and speeches on the subject of visual impairment throughout the United States and in a number of European countries, and is the author of more than 30 articles in various areas of visual impairment, technological developments, and rehabilitation.

THE DAYTON PUBLIC SCHOOLS,
Dayton, Ohio, March 12, 1984.

Hon. ANDREW JACOBS, Jr.,
Chairman, Subcommittee on Health,
Washington, D.C.

DEAR HONORABLE JACOBS: I am writing to ask for your support of H.R. 4437, the Handicapped Independence Assistance Act of 1983. The bill is aptly titled since communication aids which give the non-oral handicapped individual the freedom of speech do indeed lead to his independence.

As a speech pathologist I work with handicapped individuals who have no verbal expression. They are indeed dependent in a world of oral speech in the family, in school, in work and in society. They have lost or never had that most human of characteristics, the power of speech.

Now, as a result of technology, that non-speaking individual can through a wide selection of communication aids acquire a system of speech acceptable to his peers. He can control his behavior and his environment. He can profit from training and he can become independent.

Unfortunately very few such individuals and their families can afford these promising technological advances. Finances have been bankrupted through health costs. Third party payers are cutting back on expenditures. In today's market, it strains the best of circumstances for a family just to provide the basic medical care for a handicapped person

H.R. 4437 can provide unlimited assistance to a child bound in silence. It will allow him to take advantage of educational opportunities and become a productive person to the full extent of his capability, rather than fostering his disability.

Your support of the bill will be immeasurably appreciated by those who cannot speak for themselves. I am speaking for them when I request it.

Thank you for your time and your consideration.

Yours truly,

PATRICIA F. SKINNER,
Coordinator, Speech/Language/Audiology.

HARRY S TRUMAN CHILDREN'S NEUROLOGICAL CENTER,
Kansas City, Mo.

Hon. ANDREW JACOBS, Jr.,
Subcommittee on Ways and Means,
Washington, D.C.

DEAR SENATOR JACOBS: I am Beverly Jean Fitzwater. I will be 45 years old. I have lots of trouble with my speech. Now I am using the cybercode. It takes time for people to go into the cybercode with me. To find out what I need and it is also hard on me too. The cybercode is an arrangement of the alphabet into 4 rows. Someone else has to ask me which row the letter is in. I tell them yes or no. Sometimes I get discouraged to talk to people with the cybercode. But I need something to tell what I want to say to them. I am living at Truman Neurological Center, but I am not happy here. I want to move. It would help me to tell someone if I need a doctor and it would help me to go shopping. What I need to get and it would help me to go to church too. I am very smart I went to school at R J Delano for 25 years but I can't talk with people if they don't know the cybercode and that's very hard on me too. I want to be more independent in everything I can do for myself. I want it on my wheelchair side when I need something I can push on it. I want to get a say it all

plus which is a speech typewriter that says the letters and words that I type into it. A printer can be attached to it. You see I can use my right thumb to type. I can't do a very good job of typing. I am thankful I can type as well as I can. It costs about $2,000, and there is no way I can pay for it. It would help me if you vote for S. 1115 the Handicapped Independence Assistance Act 1983. To help me and others like me. Thank you very much.

BEVERLY JEAN FITZWATER.

DEAR SENATOR JACOBS: I join Beverly in urging you to vote for H.R. 4437 the Handicapped Independence Assistance Act of 1983. With the help of an electronic speech aid people like Beverly can become more independent. If she were able to have her own apartment, it would be much cheaper then living in an institution like she does now.

I urge your careful consideration this Act.

Sincerely,

CAROL SUBRAHMANYAM, M.A., C.C.C.,
Speech Pathologist.

GORMAN SCHOOL,
Dayton, Ohio, March 14, 1984.

Hon. ANDREW JACOBS, Jr.,
Chairman, Subcommittee on Health,
Washington, D.C.

DEAR SIR: It has come to my attention through the efforts of Pat Cashdollar, parent of a multihandicapped child and member of our area's Nonverbal Task Force, that you would welcome views concerning the current legislation before you.

As a speech and language pathologist providing services for an orthopedic setting, I am currently serving seven (7) nonverbal individuals and one (1) hearing handicapped child. These students have limited functional communication because:

(a) the use of a communication system (e.g., signing, symbol boards) requires conversation partners with some training in these systems.

(b) conventional systems are restricted by size, weight, ease of manipulation, and limited adaptability to differing situations and individuals.

(c) the students have limited opportunity to use more sophisticated equipment.

In spite of these constraints on their communication, these children demonstrate a capacity to effectively communicate when they are given the right tools and allowed enough time to compensate for inefficient modes.

I wish to affirm the remarks made by the Honorable George E. Brown on November 17, 1983 (as reported in the Congressional Record—Extensions of Remarks, E 5647). I quote: "Sensory and communication aids increase the communication abilities of those with sensory impairments—hearing, speech, and sight." Not only is this supported in the professional literature, but I have also observed this through my personal and professional experience. I would also like to applaud this later paragraph:

"Some raise questions about the cost of this proposal. I am also concerned about increased demands on already burdened Medicare and Medicaid systems. However, increasing the communication capabilities of the sensory disabled will give them greater employment and educational opportunities. Greater independence and potential for productive employment among the handicapped will reduce welfare and disability payments, reduce the number of hours necessary for attendant care and special school services, and increase Federal, State, and local tax revenues."

Right now, I am in the process of trying to obtain speech prostheses for two of the students on my caseload. Having obtained a prescription from the doctor, we are applying to a private insurer to provide funding. Not only would passage of this bill be of enormous benefit to Medicaid-eligible clients, but it would also provide much needed impetus for other insurance companies (or underwriters) to accept the speech prosthesis as a legitimate insurance benefit.

Considering the billions of dollars we spend annually on fostering dependence through disability payments, passage of this bill would be a triumph of common sense in that it would support, morally and financially, independence-generating rehabilitation.

Thank you for your time and consideration on this matter.

Sincerely,

CAROL SUDDATH,
M.A., C.C.C. Sp./L.

HAYWARD HIGH SCHOOL,
Hayward, Calif., February 27, 1984.

JOHN J. SALMON,
Chief Counsel, Committee on Ways and Means,
Washington, D.C.

DEAR MR. SALMON: The action proposed by H.R. 4437 is reasonable and desirable. It would provide appropriate support for a minimum of equipment to aid the sensorially impaired. I strongly endorse the proposal and its intent.

Sincerely yours,

JOAN T. HARRIS,
Program for Hearing Impaired.

HEARING SOCIETY FOR THE BAY AREA, INC.,
San Francisco, Calif., March 9, 1984.

JOHN J. SALMON, Esq.,
Chief Counsel, Committee on Ways and Means,
Washington, D.C.

DEAR MR. SALMON: On behalf of the thousands of hearing impaired people we serve annually, we are writing to inform you of our strong support of the above noted legislation.

People with severe sensory deficits must have communication aids if they are to maintain any semblance of independent living and/or interaction with people in their environment.

We have developed over the past several years a significant display of assistive devices for hearing impaired people and are constantly reminded of the role of such devices in helping such people retain a degree of control over their environment. The major problem we have faced is how to help people receiving Medicare or Medicaid benefits obtain these medically-necessary communication aids.

The limits recommended in the bill are reasonable and logical both in terms of single expenditures and total costs over a multi-year period.

We urge favorable consideration of this legislation and its recommendation to both the House and Senate

Yours very truly,

JOHN L. DARBY,
Executive Director.

NOTTINGHAM, PA., *January 4, 1984.*

Hon. DAN ROSTENKOWSKI,
House of Representatives,
Washington, D.C.

DEAR MR. ROSTENKOWSKI: May we please have your support of S 1115 and HR 4437 amendments to the Social Security Act, introduced by Senator Matsunaga of Hawaii and Representative George Brown.

As the father of a son who is profoundly physically handicapped by cerebral palsy (including no speech and no capacity to work a typewriter or keyboard, even with augmentative devices) but who has a measurable I.Q. in excess of 120 and who is an accomplished poet (three books published by the age of 22), I can certify to the desperate need for this legislation that would define certain sensory and communication aids as medical protheses and would enable the securing of Medicare/Medicaid coverage for these systems/devices.

Over the past ten years, as silicon chip technology has been developing, I have been working to design a communication system prothesis for him that would enable him to do work station writing, social communication, note taking and filing, electronic mail, etc. The system we are putting together is beginning to come on stream and he is right now learning to use it. At heart, it is/will be an adative firmware keyboard emulator developed at the University of Washington-Seattle coupled to an Apple IIe computer augmented by extra memory, an extended 80 character card, a CMP card, two floppy disk drives, a 10 megabyte Winchester, a green phosphor high resolution memory mapped video, micromodem, dot matric printer, programmable scanwriter, voice synthesizer, peripheral systems (power supply protection, cabinet & stand, cooling and humidity control, etc.), custom developed interface switches, and standard software packages such as Apple Writer Word Processing,

Quick File Note Taking, Sensible Speller Dictionary, Communitree Electronic Mail and Bulletin Board, etc. In the future, we plan to add systems for environmental (radio/TV/lights/thermostat/call help/etc.) control.

To date I have expended over $6000. Total estimated cost is in order of magnitude $18,000.

This system will enable my son, who is otherwise absolutely and totally helpless, to pursue a career in writing, to engage in meaningful and purposeful communication of all types common to modern man, to harness the cognitive power of computers to assist in all types of work (perhaps with access to computers, his career objectives will broaden or change), to gain access to higher education, and to control personal devices such as lighting and TV.

It really offers meaningful life and hope where before there was total emptiness, frustration, and despair.

According to a 1977 estimate by the Bureau of Education for the Handicapped, there are 1,414,000 allolingual persons in the United States. Most of them are not as profoundly and severely handicapped as my son. Nearly all of them need and could profitably use communication protheses. Probably the delivered cost for most of them would be in the $4000–$8000 range, depending on degree of handicap.

I have been given the run-a-round by Medicaid. We have been refused coverage and reimbursement by our health insurance provider on the grounds that this is a "teaching tool" and not a medically necessary communication prothesis (we have, however, considerable professional testimony, clinical evaluations and recommendations, and doctor's prescriptions to the contrary). We are just now beginning the awesome task of fighting our way uphill against an established health care funding system that prefers to not see a communication aid as a medical prothesis.

Legislation such as S1115 in the Senate and HR4437 in the House are essential if we are to provide maximum access to life for the many more handicapped persons in our country who need communication protheses.

Thank you very much for hearing me. We know we can count on good people such as yourself for your help. If I can answer any questions please call at 215-447-1157 or 215-932-3591 or write

Very Thankfully Yours,

JOHN O. KINNAIRD.

BETHESDA, MD., *March 15, 1984.*

JOHN J. SALMON,
Chief Counsel, Committee on Ways and Means,
Washington, D.C.

DEAR REPRESENTATIVE SALMON: I am writing in support of HR4437, the Handicapped Independence Act. It is essential that the severely communicatively handicapped be given the opportunity to use existing advanced communication technology to allow them to be functionally independent and useful in society.

Very sincerely,

MARSINAH MAZUZAN,
Graduate Clinician.

NEUROLOGICAL REHABILITATION ASSOCIATES,
Waynesboro, Va., March 13, 1984.

Hon. ANDREW JACOBS, Jr.
Chairman, Subcommittee on Health,
Washington, D.C.

DEAR MR. JACOBS: I am writing in support of H.R. 4437, The Handicapped Independence Assistance Act of 1983. As a speech-language pathologist, I frequently come in contact with persons in need of communication aids. It is apparent to me that providing a necessary communication aid is a big step toward independence and increased productivity for clients. Unfortunately, many times it is also apparent that the need for a communication system goes unmet—primarily due to lack of available funding. Funding through Medicare and Medicaid could help this gap between need and affordability.

Certainly, one can agree that a prosthesis for an amputee is medically necessary. It seems natural, then, to view a speech synthesizer in the same light—a "speech

prosthesis" for an individual who has lost (or has never had) the ability to communicate orally.

No one feels this more than a non-vocal person. In an article in ASHA (August, 1981), Ricky Creech, a person with severe cerebral palsy who uses a speech synthesizer (HandiVoice) to communicate, stated, "I think the reason the public finds it especially difficult dealing with people who either can't hear or speak is because these are the two abilities we use in communication. People are used to being able to speak while another listens and listen while another speaks. This is the conventional way of communicating. People become very uncomfortable in a situation which calls for an unconventional way of communicating. They back off from these situations. This is why the HandiVoice is so important to me, it allows me to speak with people in the conventional way—orally." (page 551)

Clearly, if this legislation were passed, it would be responding to basic human needs. It would promote greater independence and enhance potential for productive employment, not to mention improve quality of life for hundreds of thousands of children and adults.

Thank you for your time.

Sincerely,

JOAN A. RAWLINGS,
M.A.-CCC-SP.

THE NORTH CAROLINA MEMORIAL HOSPITAL,
Chapel Hill, N.C., March 12, 1984.

Hon. ANDREW JACOBS, Jr.,
Chairman, Subcommittee on Health,
Washington, D.C.

DEAR MR. JACOBS: As the Director of the Speech Pathology Service here at North Carolina Memorial Hospital and as a fulltime speech/language pathologist, I wish to encourage you to do all you can to further the case of H.R. 4437. For years now we have been evaluating patients and finding them capable of using some of the newer electronic and microcomputer communication devices, however, ultimately the patient is unable to obtain the device due to the failure of third party carriers to fund them.

In my ten years here at North Carolina Memorial Hospital I have had a large number of young adults who have suffered a number of injuries which resulted in unintelligible speech although they were ambulatory and capable of returning to work in some capacity. The fact that they were unable to communicate vocally was one of the primary reasons that they failed to be re-employed. With the advent of the newer communication devices now available on the market, we are able to assist many of our patients in enabling them to once again communicate with their families, friends and potential employees. Unfortunately, the cost of many of these devices ranges from $300.00 to $3,000.00. When placed in the context of returning to work for years in the future with the concomitant taxes being collected from people gainfully employed, the initial cost of 80% of such communication device pales in comparison.

These are just a few examples of the many patients who would ultimately benefit from the use of a communication device which presently is not being funded by third party carriers, specifically Medicare.

Thank you for your consideration in this matter. If you desire further information or have additional questions, please do not hesitate to contact me.

Sincerely,

STANLEY J. MARTINKOSKY, Ph.D.,
Director, Speech Pathology Services,
Hearing and Speech Center.

STATEMENT OF SELF HELP FOR HARD OF HEARING PEOPLE, INC., BY HOWARD E. STONE, SR., PRESIDENT

Mr. Chairman: I regret my inability to appear for scheduled testimony before your committee on February 27th, but I am pleased to submit my statement to you in written form.

Self Help for Hard of Hearing People (SHHH), of which I am President, is the largest organization of hard of hearing people in the United States. In our four years of existence, more than 7,000 persons have joined forces to find ways of coping

with their hearing loss. Many of our members have severe hearing impairments and they are interested in sensory and communication aids as a means of acquiring education, gaining (and keeping) employment, and, in general, of staying in the mainstream of life.

For these reasons, SHHH is pleased to support H.R. 4437, the "Handicapped Independence Assistance Act of 1983". Within the context of our support, we have several comments:

Financial caps: the limitation of $5,000 on the device in any one calendar year with a maximum coverage of $15,000 in any five consecutive calendar years, seems to us, appropriate. We are a self help organization and while we recognize the need for government assistance to those most urgently in need of high cost technology, we endorse the concept of individual responsibility for costs in excess of the covered amount. The legislation thus becomes part of a community effort rather than simply seeking governmental solutions.

Within the financial caps, we endorse the recommendation of the Office of Technology Assessment, that the cost of repairs and maintenance should also be a covered expense.

Finally, we are skeptical about cost figures based on projected usage in a short timeframe, should this legislation pass. With regard to hearing impaired people, a look at two different economic systems which have experience in this area might be constructive. In socialist England, provisions of free hearing aids has not resulted in their usage by even a majority of those who could benefit from amplification. In the state of California, in over three years of distribution, far fewer deaf people have availed themselves of free TDD's (teletypewriters for the deaf) than projections indicated. (Some 15,000 vice 200,000.) The point here is that human reaction to technology results in far less use of such devices that statistics indicate. Motivation as well as need determines usage. The cost to government then, would be less for this legislation than most critics think.

The delivery system in H.R. 4437 seem to assure the current Medicare practice requiring a physician's prescription for implementing the program. As a consumer organization in close touch with its membership, we state with confidence that very few physicians know anything about assistive devices for hearing impaired people. In this area, the audiologist plays the key role. We would like to see the wording changed in relation to sensory and communications aids for hearing impaired people.

While we support this legislation, we agree with the American Speech-Language-Hearing Association (ASHA) that hearing aids should be explicitly included. The bill specifies "severely hearing impaired" as recipients of aids under discussion and that specificity greatly reduces the number involved. And, as indicated above, we believe the estimates of usage which make up cost analysis are greatly exaggerated (at least for hearing impaired people).

Conclusion: H.R. 4437 is a step in the right direction. It encourages government, private sector and consumer cooperation. While leading the way it ensures shared responsibility in ameliorating handicapping conditions in America—a sensible approach for the eighties. The language of the proposed legislation restricts participation to "severely hearing impaired" or "deaf" people and thus addresses the area of greatest need. SHHH supports the "Handicapped Independence Assistance Act of 1983".

POTOMAC, MD., *March 15, 1984.*

JOHN J. SALMON,
Chief Counsel, Committee on Ways and Means,
Washington, D.C.

DEAR REPRESENTATIVE SALMON: I am writing in support of HR4437, the Handicapped Independence Act. It is essential that the severely communicatively handicapped be given the opportunity to use existing advanced communication technology to allow them to be functionally independent and useful in society.

Very sincerely,

BARBARA C. SONIES, Ph.D.,
Speech Language Pathologist.

UNIVERSITY PARK, MD., *March 15, 1984.*

JOHN J. SALMON,
Chief Counsel, Committee on Ways and Means,
Washington, D.C.

DEAR MR. SALMON: I am writing in support of HR 4437, the Handicapped Independence Act. It is essential that the severely communicatively handicapped be given the opportunity to use existing advanced communication technology to allow them to be functionally independent and useful in society.

Very sincerely,

MAUREEN STONE, Ph.D.,
Research Consultant,
Speech Pathology.

HUBER HEIGHTS, OHIO, *March 9, 1984.*

Hon. ANDREW JACOBS, Jr.
Chairman, Subcommittee on Health,
Washington, D.C.

DEAR REPRESENTATIVE JACOBS: It has come to my attention through the efforts of Pat Cashdollar, parent of a multihandicapped child and member of our area's Non-Verbal Task Force, that you would welcome views concerning the current legislation before you.

As a Speech/Language Pathologist in a public school setting, I am currently serving as consultant for the Severe Communication and Behavior Disordered (S.C.B.D.) Program, Montgomery County Board of Education, which includes 10 nonverbal individuals and 3 hearing impaired children. These students currently have limited functional communication because of 1.) the use of a communication system (e.g. signing or symbol boards) that is not understood by untrained communication partners and 2.) communication systems that are limited by size, weight, ease of use and adaptability to the individual and different communication situations (e.g. home versus school).

I wish to reiterate the remarks made by Hon. George E. Brown, Jr. in the November 17, 1983 issue of the Congressional Record—Extensions of Remarks E5647. And I quote, "sensory and communication aids increase the communication abilities of those with sensory impairments—hearing, speech and sight." This premise is supported by the speech and language literature and by my own professional experience.

Again, quoting from the forementioned source:

"Some raise questions about the cost of this proposal. I am also concerned about increased demands on our already burdened medicare and medicaid systems. However, increasing the communication capabilities of the sensory disabled will give them greater employment and educational opportunities. Greater independence and potential for productive employment among the handicapped will reduce welfare and disability payments, reduce the number of hours necessary for attendant care and special school services and increase Federal, State and local tax revenues."

I am currently in the process of obtaining a speech prosthesis for an individual on my caseload and will certainly apply for private insurance funding. Not only would passage of this bill be of enormous benefit to medicaid eligible clients, but it would also provide much needed impetus for other insurance providers to accept the speech prosthesis as a legitimate insurance benefit.

Considering the billions of dollars we spend on fostering dependence through disability payments, passage of this bill would be advantageous in that it would support (morally and financially) independence-generating rehabilitation.

Thank you for your time and consideration.

Sincerely,

JACKIE L. SUSNIK,
M.A., C.C.C.

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